

Developing a Process of Risk-Stratified Care Coordination for Older Adults in Primary Care

by

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A thesis
presented to the University of Waterloo
in fulfillment of the
thesis requirement for the degree of
Doctor of Philosophy
in
Health Studies and Gerontology (Aging, Health and Well-Being)

Waterloo, Ontario, Canada, 2016

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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.

I understand that my thesis may be made electronically available to the public.

ABSTRACT

BACKGROUND

Older Canadians with chronic diseases are the highest users of the health care system. Primary health care (PHC) could play a central, coordinating role in assessing older adults and managing their care, but at present lacks specific strategies to fulfil this role. Priorities for enhanced care coordination in PHC include: 1) consistent processes to identify and assess older persons and create individual care plans aligned with risk levels; 2) improved care coordination and system navigation; 3) improved access to appropriate services; and 4) improved patient and caregiver engagement (Heckman et al., 2013; World Health Organization, 2008; Wagner, 2000; Goodwin et al., 2013). This dissertation project aims to understand how a process of risk-stratified care coordination for older adults can be developed and implemented in primary care. Information gathered to answer this question will provide an in-depth understanding of: i) the local context where the process is implemented, including available health and support services; ii) the process of implementing a screening and referral process in primary care, and iii) the experiences of providers, patients and caregivers with implementation to see how the process might be modified and to understand what factors are important for future spread.

METHODS

The Chronic Care Model (Wagner et al., 1999), a framework to guide care improvements and a multi-level (environmental, organizational, patient, provider, and program) framework for implementation of health innovations (Chaudoir et al., 2013) were used to guide the three study phases. Overall data collection and analysis followed a mixed methods design, within a developmental evaluation approach. Data were collected using ethnographic observations (phases 1,2,3), informal feedback (phase 2), individual and focus group interviews (phases 1 and

3), and survey (phases 1 and 3) and tracking forms (phase 3). Data were analyzed using appropriate qualitative and quantitative techniques. Patients, family caregivers, and health care providers were purposefully sampled from two Family Health Teams in Ontario (rural and urban).

RESULTS

Through focus group interviews with health care providers, lack of care coordination, information sharing, patient engagement, and service awareness were identified. To address these concerns, a process of risk-screening and care coordination for patients 70 + years of age was developed and implemented through an iterative process, in two primary care clinics. 512 patients were screened for level of risk using the interRAI Assessment Urgency Algorithm (AUA) and care was coordinated for individuals based on level of need. Among those screened, 70% of individuals screened as low risk, 25% were screened as moderate risk, and 5% were screened as high risk. As a result, service referrals were made to self-management, community programs, and specialized geriatric services using an online referral mechanism. Although the screening and referral process is time consuming, health care providers, patients and caregivers identified many benefits including early identification of service need, greater awareness of services available in the community, and improved relationships between patients and providers.

CONCLUSIONS

A process of risk-stratified care coordination was developed and implemented in primary care through an ongoing, iterative process with older adults, caregivers, and health care providers. Future research activities should focus on testing these findings in other models of care (e.g. solo-physician practice) and in other regions.

ACKNOWLEDGMENTS

I would first like to thank Dr. Paul Stolee for his mentorship, guidance and friendship throughout my doctoral training. I am very grateful for the opportunities he has provided me with to develop my skills and knowledge, share my research and build my career. I have learned so much from Dr. Stolee including strong leadership and rigorous research and evaluation skills. Your passion for improving the geriatric health care system and mentoring students has greatly influenced my program of research and academic career.

I would also like to thank my committee members, Drs. George Heckman, Veronique Boscart and Lora Giangregorio, for their support throughout my training. Thank you Dr. Heckman for your guidance, collaboration and motivation. Thank you Dr. Boscart for your knowledge and mentorship regarding my qualitative research skills. Thank you Dr. Giangregorio for pushing me to think outside of the box. I would also like to thank my internal/external examiner, Dr. Colleen McMillan, and my external examiner, Dr. Ruta Valaitis for their interest and willingness to review this dissertation, and for providing comments and suggestions that will aid in publication of the research and development of future research projects.

I would also like to thank Ms. Susie Gregg and Ms. Jane McKinnon-Wilson for their support, motivation and friendship. Ms. Gregg and Ms. McKinnon-Wilson, you have provided me with invaluable knowledge about the health care system and I am very grateful to have had the opportunity to collaborate with you both.

I would also like to acknowledge the individuals who participated in this research project. To the health care providers and managers, thank you for your dedication to this project. To the older adults, thank you for taking the time to speak with me, your personal experiences and

insights were invaluable to this project. And, a special thank you to members of the SHARP group for your ongoing support and dedication to improving the health care system through collaborations with our research group.

My research would not have been possible without the funding support from: i) Technology Evaluation in the Elderly Network (TVN) – Interdisciplinary Fellowship Award; ii) St. Joseph’s Health Centre Guelph – Waterloo Wellington LHIN; iii) Canadian Institutes of Health Research – InfoRehab Team Grant; and iv) University of Waterloo – School of Public Health and Health Systems.

I would also like to thank my colleagues with the Geriatric Health Systems Research Group for making my doctoral training so enjoyable. A special thank you to Sheila Bodemer and Heather McNeil for your ongoing support and friendship.

Last but never least, thank you to my family who instilled in me a passion for learning and caring for others. To my father, thank you for your constant love, support and guidance. To my late mother, thank you for your love, support and passion for teaching. I miss you each and every day. To my brother, Jonathan, thank you for your friendship, wisdom and constant support. To Laura, Yianni and Ruby, thank you for your ongoing love. To the Penners, thank you for your love and support over these last few years. To Mike, thank you for sharing in this journey with me and for your continuous love, encouragement and support. Without the love and support of my family, the completion of my PhD training would not have been possible.

DEDICATION

I dedicate my dissertation work to my family who have supported me throughout this process.

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1.0 INTRODUCTION AND OVERVIEW

Older adults with chronic diseases are the highest users of the health care system (Rothman & Wagner, 2003; Public Health Agency of Canada, 2011). Currently, the health care system is not well designed to coordinate care for persons with complex health problems who require services from multiple care providers, across multiple care settings. Primary health care (PHC) is seen as having a role in coordinating care for frail older adults (Heckman et al., 2011), but currently lacks resources and strategies to fulfill this responsibility. Older adults and their families would benefit from care coordination and navigation through the complex and often fragmented health care system (Wagner, 2000). However, the level and type of navigation required depends on the complexity of the patient's problems, current resources, and the variety of services required (Liss et al., 2011). Risk assessment, continuity of care, and engaged patients and families have been found to result in better health outcomes (WHO, 2008). This project aims to understand how a model of risk-stratified care coordination for older adults can be developed and implemented in primary care. This work was conducted in two Family Health Teams (FHT), a team-based primary health care organization in Ontario, Canada.

Using a concurrent transformative design (mixed methods) within a developmental evaluation approach, this project aimed to understand how a process of risk-stratified care coordination can be developed and implemented in primary care. This thesis project was completed in three phases (see Figure 1.0 below):

Phase 1: Understanding the Context (Chapter 4)

Individual and focus group interviews were conducted with community health care

providers and primary health care providers to understand current referral processes and methods for care coordination. In total, three focus group interviews (involving 4-6 health care providers/focus group) and six individual interviews were conducted with health care providers from two primary care teams and community care organizations. Six key themes were identified and were mapped onto the Chronic Care Model (Wagner et al., 1998). The results of this study provided an in-depth understanding of the current context in which the primary care teams are currently operating. Improved primary care will require stronger processes of coordination, and greater knowledge of and connections with other community services. This information provides a helpful basis for implementing interventions in primary care.

Phase 2: Using Developmental Evaluation to Improve Care Coordination (Chapter 5)

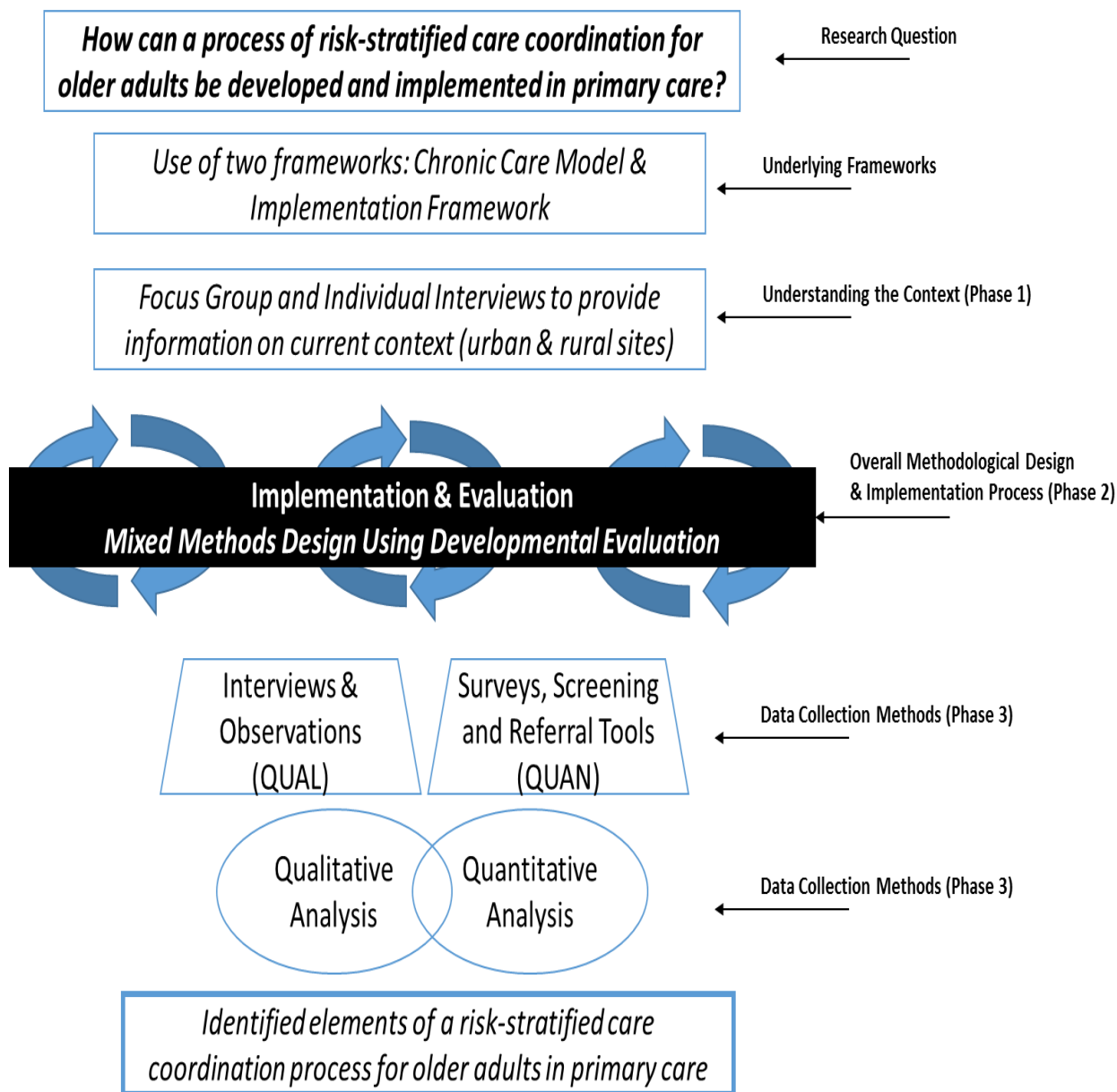
Developmental evaluation is an appropriate approach for evaluating changes with complex systems. Health care systems have become increasingly complex and consequently, there is growing recognition of the relevance of complexity theory to understand health system functioning, and to guide health care research and evaluation (Plsek et al., 2001; Counsell et al., 2007; Guzman et al., 2008). A developmental evaluation approach was used to develop and implement improved care coordination using a screening and referral process for older patients in two primary care settings (one urban, one rural), over a period of six months. The Implementation Framework of Chaudoir and colleagues (2013) was used to guide implementation. Elements of an improved care coordination process were identified collaboratively, and informal feedback was gathered throughout the implementation process to inform modifications. Lessons relevant for future implementation of innovations in primary care were identified.

Phase 3: Coordinating Care for Older Adults in Primary Care (Chapter 6)

In phase 3, data were collected using ethnographic observations; individual interviews with health care providers, patients and caregivers; and survey and tracking forms. Data were analyzed using qualitative and quantitative techniques.

Screening for level of risk was completed for 512 patient using the interRAI Assessment Urgency Algorithm (AUA) and care was coordinated for individuals based on level of need. Based on the identified level of risk, service referrals were made to self-management supports, community resources, and specialized geriatric services using an online referral mechanism, Caredove. Overall, it was found that a process of risk-stratified care coordination is possible in team-based primary care settings, however taking the time to have meaningful conversations with patients is still a challenge, and organizational structures and funding models may need to be modified to support fuller implementation.

Figure 1.0. Research Project Overview



This research yielded a process for coordinating risk-stratified care for older complex adults in a primary care setting. These learnings will be disseminated through publications in peer-reviewed journals and conference presentations, and by policy and practice partners in the Waterloo Wellington Local Health Integration Network (WWLHIN; LHINS are regional

health authorities responsible for planning, integrating, and funding local health care services (Ontario's LHINs, www.lhins.on.ca).

1.1 Reflexive Standpoint

When conducting qualitative research, it is important to be reflexive during interviews and while gathering information. Reflexivity in qualitative research is described as “thoughtful, conscious self-awareness” (Finlay, 2002, p.532). In terms of ethnographic research, Finlay (2002) states, “the reflexive ethnographer does not simply report facts or truths but actively constructs interpretations of his or her experiences in the field and then questions how these came about” (p.532). Although being reflexive indicates reflection of oneself, it is also the process of continuous self-awareness of experiences throughout the research project.

My interest in exploring care coordination in primary care stems from past research experiences during my Master's training. I was involved in the CIHR InfoRehab project where hip fracture patients were followed and interviewed at each transition point during their rehabilitation journey. This work identified key areas for future research including, better engagement of patients and caregivers in decision-making, enhanced communication across the system and improved access to appropriate services when necessary (e.g., Elliott et al., 2014; Toscan et al., 2014; Giosa et al., 2013; Sims-Gould et al., 2012). Upon entering the PhD Program at the University of Waterloo, I had the opportunity to attend Waterloo-Wellington Geriatric Services Network meetings – a committee that aims to improve the geriatric health care system in the region and that reports directly to the Local Health Integration Network. Through this work it was clear that there were issues with coordinating care for older adults in the community, further validating the results from the InfoRehab project. I had to be constantly aware of the fact that I bring past research and health system experiences into this thesis

project.

I also wore many ‘hats’ throughout this project. First and foremost, I was a *researcher*, and collected and analyzed data following appropriate methodological techniques. I was an *implementer and educator*, and trained health care providers on using the risk screening and referral mechanisms. I was an *evaluator*, immersing myself into the primary care teams to understand the implementation process and experiences of participants. Lastly, I was a *knowledge facilitator*; this role included presenting information at local health system meetings, provincial webinars and national and international conferences.

Throughout the thesis project, I was aware of the roles that I played and understood the biases that may have occurred as a result. While it is possible that these roles and potential resulting biases may have influenced my analysis and interpretations of the data, playing multiple roles was also a strength of the methods I used. I was deeply embedded into the project and processes which allowed me to gain an in-depth understanding of patient and provider experiences and the functions of primary and community care. Frequent meetings with project team members and my supervisor allowed me to understand my preconceived biases. During the analysis period there were times where I had to step back, re-group, reflect on my past experiences and then proceed forward. By reading through the transcripts multiple times, I was able to determine which ideas were expressed strongly by many of the participants and truly emerged from the data. These ideas helped to create the themes that are discussed in this thesis and provide an in-depth understanding of participants’ experiences.

2.0 REVIEW OF THE LITERATURE

2.1 Introduction

Chronic diseases are a major cause of disability in older adults, and a primary reason for physician visits (Rothman and Wagner, 2003). In 2010, treatment of chronic diseases in Canada accounted for more than half (\$68 billion per year) of direct health care costs and \$122 billion of indirect costs (income and productivity losses) (Public Health Agency of Canada, 2011). These numbers will continue to increase as the population ages.

In 2008, 76% of older adults reported having one or more chronic conditions, and 24% reported having three or more chronic conditions (CIHI, 2012). Older adults are often classified as ‘complex’ as they often experience multiple chronic conditions and functional disabilities that require a variety of health care services (Findlay et al., 2010). Those with multiple conditions report poorer health, higher rates of health care visits, and require a number of health care providers to be involved in care, often making it difficult to coordinate care (CIHI, 2012).

Frailty

As the population ages there will be a growing number of *frail* older adults. This group of older adults frequently have complex health problems, multiple chronic conditions, and dependency in activities of daily living (ADL) (Fried et al., 2004). Although there is still no agreed upon definition of frailty, frailty is generally regarded as a state of vulnerability for adverse health outcomes (Fried et al., 2004; Lacas & Rockwood, 2012). Adverse health outcomes may include; disability, dependency, need for long-term care, falls, and mortality (Fried et al., 2004).

Lacas and Rockwood (2012) conducted a review on identification of frailty in primary care and concluded that there is currently no standard screening tool for frailty in primary care.

Many of the articles included in the review stated that work in the area of frailty in primary care, specifically around instruments to identify frail patients is still in its infancy (Lacas & Rockwood, 2012). More recently, O’Caoimh and colleagues (2015) conducted a systematic review of case-finding instruments for use in community care settings that can predict adverse health outcomes. Twenty-three instruments were identified, however the review concluded that there is a need to “develop a short, reliable, valid instrument to case-find older adults at risk in the community” (p.1). The proposed research project is consistent with current research aimed at identifying older persons who may be risk and for whom further assessment and intervention is needed, and those who may not yet be frail (pre-frail or healthy) for whom preventive efforts could be beneficial (Lacas & Rockwood, 2012; O’Caoimh et al., 2015).

Models of Care

Delivery of seamless integrated care has become a central concept in the ongoing development of care models (Boeckstaens et al., 2011). The World Health Organization (WHO) has defined integrated service delivery as, “*the management and delivery of health services so that clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system*” (WHO, 2008). Primary health care could play a role in organizing care and managing chronic conditions for older adults, however, the current health care system is not well equipped to deal with the needs of complex older adults (Rothman & Wagner, 2003). Care is often difficult to coordinate and a health system that often operates in a siloed rather than in an integrated fashion is challenging to navigate (Béland et al., 2006). This can result in older adults not receiving timely or effective care.

Health Council of Canada (2005) defined primary health care as a community- based

setting that provides information on illness and injury prevention, health promotion, diagnosis and treatment of health conditions, and rehabilitative care. The primary health care system needs to move away from its emphasis on episodic care (patients seek attention for specific, acute complaints and leave when treatment has been received) to providing continuous care for individuals with chronic conditions. Models of primary care need to become more patient-centred and more collaborative so that care is organized around the patient, who may access services across multiple settings, organizations and providers (Van Houdt et al., 2013; Sevin et al., 2009; Kingston-Riechers et al., 2010). Improving the primary care system can result in better health outcomes for patients, and an overall decrease in health care costs (Starfield et al. 2005). This may be achieved through the use of standardized assessments and individual care plans, improved coordination of care, and better communication and engagement between providers, patients, and families. These elements have been identified as key components needed for an enhanced model of care (Goodwin et al., 2013). Furthermore, primary care has been identified as the location where care coordination should occur because, *“primary care is an anchor for patients and families and is well-positioned to coordinate care in the system. Primary care should be the first contact or entry into the system. Primary care should organize and activate the deployment of health care resources”* (Ontario Primary Care Council, 2015, pg. 5). The following section provides more information on the key components outlined by Goodwin and colleagues (2013) which will be important for the development of a process of risk-stratified care coordination for older adults.

2.2 Coordinating Care across the System

Care coordination is an important focus because of the potential for significant impact on patient outcomes and overall health care delivery (Ontario Primary Care Council, 2015).

Care coordination has been defined numerous ways in the literature, with one review finding 40 distinct definitions of care coordination (McDonald et al., 2007). For the purposes of this thesis project, care coordination has been defined as “*a person-centred, assessment-based, interdisciplinary approach to integrated health care and social support services in a cost-effective manner in which an individual’s needs and preferences are assessed, a comprehensive care plan is developed, and services are managed and monitored by an evidence-based process which typically involves a designated lead care coordinator* (National Coalition on Care Coordination, 2011). Through an analysis of the care coordination definitions, McDonald and colleagues (2007) identified five key elements including: i) numerous participants are involved in coordinating care; ii) coordination is necessary when participants are dependent upon each other to carry out disparate activities in a patient’s care; iii) each participant needs adequate knowledge about their own roles and the roles of others and available resources; iv) participants rely on information exchange; and v) integration of care activities should facilitate appropriate delivery of services. Other key components of care coordination include: engagement in decision-making through relationship building with the patient, assessment of the patients’ functional health and social needs, and developing care plans and making necessary referrals (Ontario Primary Care Council, 2015). The term care coordination is often used interchangeably with terms such as care management, case management and navigation.

Regardless of the term or definition used, Goodwin and colleagues (2013) have outlined characteristics of successful approaches for coordinating care at system, organizational, clinical and services levels. These are displayed in Table 2.1 below. These components should be included when designing an integrated, coordinated model of care.

Table 2.1 A sample of characteristics that support successful care coordination

<i>Level</i>	Characteristics supporting care coordination
<i>System</i>	<ul style="list-style-type: none"> • Primary care or community care led • Emphasis on chronic or long-term care • Alignment with goals of integrated care • Educated workforce, skilled in chronic care and teamwork
<i>Organizational</i>	<ul style="list-style-type: none"> • Strong leadership • Common values
<i>Clinical Integration</i>	<ul style="list-style-type: none"> • Use of risk stratification • Joint care planning
<i>Service Integration</i>	<ul style="list-style-type: none"> • Single point of entry • Coordination (care coordinator) • Supported self-care • Interprofessional team • Centralized referral process

Care coordination attempts to integrate the care of a patient among multiple health care providers, across different organizations. Patients and families need support in understanding how to access the right services, at the right time (Sinha, 2012). The level and type of navigation required depends on the complexity of the patient’s problems, their current resources, and the diversity of services (Liss et al., 2011). Providing care for older adults can be complicated for both health care providers and family caregivers. When working with older adults, health care providers often experience poor communication and have difficulty coordinating continuous care (Sims-Gould et al., 2011). Family caregivers may have inadequate social support, experience caregiver burnout, workplace consequences, and disengagement from care decision-making (Aggar et al., 2010; Baumgarten et al., 1992). These issues may negatively impact the quality of care that informal caregivers and service providers are able to offer to patients.

Many suggest that a “system navigator” or “care coordinator” could provide valuable

assistance to patients and family caregivers as they navigate through the system (Manderson et al., 2012). There are a number of different health care providers within the system who can take on the role of coordinating care for patients and function as a system navigator. These might include a health coach, case manager, personal support worker, social worker, or nurse practitioner. Table 2.2 provides information on some of the current “navigator” roles in the system.

Table 2.2 Current System Navigator/Care Coordination Roles

<i>Role</i>	Strengths and Limitations
Intensive Geriatric Service Workers (IGSW) (Paul, J. & Higgs, H., 2010)	<ul style="list-style-type: none"> • Strengths: For frail older adults who need assistance accessing services in the community after discharge from hospital; provide support to patients; work closely with primary care, specialty care, community care; accompany seniors to appointments • Limitations: Patients can only be referred by geriatric emergency management nurses, or specialist services; referral after discharge from hospital; for highly complex individuals
Patient Navigator for Cancer Patients (Wells et al., 2008)	<ul style="list-style-type: none"> • Strengths: Assist patients by providing care coordination (diagnostic or treatment care from multiple providers, filling out paper work, scheduling appointments); provide information/education to patients; provide psychosocial support; assist with transportation; provide assistance across care continuum • Limitations: Mainly focus on breast, cervical, colorectal, and prostate cancer and focus on individuals who are most at risk for poor outcomes and underserved populations
Transition Coach (Coleman et al., 2006)	<ul style="list-style-type: none"> • Strengths: Coach linked with patients and caregivers to encourage more active role during transition, provide continuity across settings, and ensure patients’ needs are met; discusses medications, personal health records, schedules follow-up with primary care, and provides knowledge to patient and caregiver about

	<p>“red flags”, indicating when a condition worsens</p> <ul style="list-style-type: none"> • Limitations: Only available for patients being discharged from hospital to community dwelling, the coach does not connect with providers, but rather encourages patients and families to, only had contact for 30 days
<p>Volunteers (eg. The TAPESTRY project, McMaster University - http://healthtapestry.ca/)</p>	<ul style="list-style-type: none"> • Strengths: Use trained community volunteers who will visit patients in their home, provide social support, collect health information (goals, nutrition status, fitness levels, etc.); enhance self-management • Limitations: Volunteers will have limited geriatric or health system knowledge
<p>Guided Care Model (Boyd et al., 2008)</p>	<ul style="list-style-type: none"> • Strengths: Specially trained, practice-based nurse would conduct compressive assessments and create a coordinated care plan for patients. • Limitations: Only available for patients identified as heavy users of health services

Regardless of who provides the navigation, a role based in primary care and integrated across the system could be of benefit to older adults. In some cases, if individuals with less complex conditions are given the right amount of information and guidance, they may be able to navigate the system themselves.

2.3 Risk Screening for Older Adults

The WHO states that 70% of chronic diseases are preventable if identified early (WHO, 2005). Screening tools are often used for early identification of those who need further assessment and who can benefit from interventions (Keller et al., 2007). Risk-stratification models can also be efficient tools to screen for older adults who may be at risk for hospitalization and functional decline (Haas et al., 2013). However, there is a lack of consistency in methods for screening and assessing older adults which has resulted in

inefficient assessment processes and confusion among care providers (Stolee, 2010).

Adopting a standardized screening and assessment method that supports consistent language, consistent development of care plans, and more efficient communication between care providers (Heckman et al., 2013; Challis et al., 2004) would be beneficial. Standardized approaches have been shown to improve care quality and outcomes (Boorsma et al., 2006). Although standardized approaches have clear benefits, primary care settings have limited time to complete comprehensive assessments, therefore assessments in primary care need to be efficient.

After completing an assessment, care pathways and resources can be organized to benefit the person at their identified risk level. Individualized care plans aligned with patient needs and risk levels allow for coordination of care and support across multiple providers and multiple organizations. A review conducted by Ovretveit (2011) found that care coordination based on risk identification of individuals led to cost savings and an increase in quality of care.

2.4 Patient Engagement & Role of Informal Caregivers

Patient and citizen engagement has been recognized as an important element in health care redesign; engagement of patients and their caregivers is essential to disease prevention and self-management (Brand et al., 2007). Patient engagement has also been recognized as a key component to successful models of care coordination (Agency for Healthcare Research and Quality (AHRQ), 2015; Ontario Primary Care Council, 2015; McDonald et al., 2007). Patient involvement, client engagement, public involvement, patient-centred care, and other terms have been used to describe patient engagement. For the purposes of this thesis, the term “patient engagement” will be used and defined as, “a relative term subjectively defined by individuals or groups/organizations that are planning to actively involve patients and their

families in various health care advisory committees or care decision making” (Gallivan et al., 2012, p.4).

Patient and caregiver engagement in care can improve patients’ quality of care, efficiency, and health outcomes (Coulter & Ellins, 2007, Coulter et al., 1999). Self-management of chronic conditions was more successful when there was a shift to actively engage patients in their own care (WHO, 2008). Patients and caregivers are the only common thread as they move throughout the care system, and therefore should have knowledge and be engaged in decision-making as they transition from one health setting/organization to another (Coleman et al., 2006; Elliott et al., 2014).

Engagement in decision-making allows for patients and caregivers to be actively involved in the care process, and to work collaboratively with health care providers to ensure that care plans are aligned with patient needs and goals (Elliott et al., accepted). Family caregivers want more input into health related decision-making and to be full partners in the care of their family member (Piraino, 2012). Evidence suggests that while patients and caregivers want to play a role, they are currently unsupported by primary health care (Giosa et al., 2014).

2.5 Summary and Implications

Principles of care coordination in primary care could improve the care experience for older adults and their family caregivers. Currently, the health system operates in silos with limited communication and information sharing within and between health care settings. This research project has the potential to improve health system integration, and develop of a more appropriate primary care system for older adults through a risk-stratified approach.

Although care coordination and integration of services has been recognized as a priority (Sinha, 2012) there is still a lack of understanding of what an integrated model of care might

look like in primary care. Prior research, literature reviews, and stakeholder consultations have identified a need for better care coordination for older adults (Elliott et al., 2013; Toscan et al., 2013; Manderson et al., 2012; Heckman, 2011). This project aimed to understand how a process of risk-stratified care coordination can be developed and implemented in primary care, and its subsequent effect on patient, family, and provider experiences

3.0 RESEARCH OBJECTIVES AND GENERAL METHODOLOGY

3.1 Research Question

This study aimed to answer the question: *How can a process of risk-stratified care coordination for older adults be developed and implemented in primary care?*

To answer this question, information was gathered to provide an in-depth understanding of the following sub-questions:

1. What is the local context in which primary care teams were operating, including the available health and support services?
2. What are the factors influencing the implementation process, including organizational and environmental barriers and facilitators to use of processes for improved care coordination?
3. What are the perceptions and experiences of *providers* with implementation of care coordination processes, to inform how these processes should be modified or to understand factors important for future implementation? and
4. What are the perceptions of *patients and caregivers* with implementation to see how processes might be modified and to understand what factors are important for future implementation?

5. Does implementation of processes for improved care coordination affect providers' satisfaction with team functioning and service delivery?

3.2 Conceptual Framework

This thesis project was guided by two frameworks, i) the Chronic Care Model to support care improvement and integration and ii) the Implementation Framework to support the implementation of health service programs.

3.2.1 The Chronic Care Model

The Chronic Care Model (CCM) is a well-established framework for guiding chronic care improvements in practice (Fiandt, 2006). The CCM has been used internationally and there is strong evidence supporting its use for health care improvements (Barr et al., 2003; Wagner et al., 2001). The CCM has been the basis for the development of other models including the Expanded Chronic Care Model (Barr et al., 2003) and the Guided Model of Care (Boult et al., 2008), however the CCM is well-known and readily understood by researchers and policy makers and therefore will be used to guide this thesis work.

The CCM, illustrated in Figure 3.1, is made up of six components for health care delivery: productive interactions; clinical information systems; delivery system design; decision support; self-management support, and community resources. Improvements to care practice should be made based on all of the components, however if only some of the components are being addressed, keep in mind the effect on other components of the model (Fiandt, 2006).

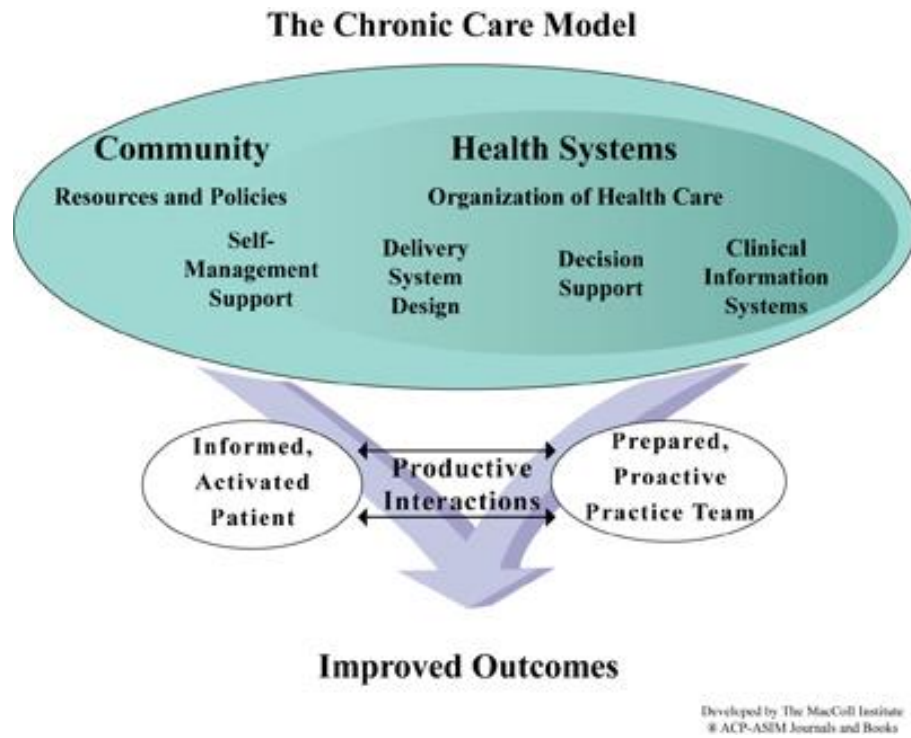


Figure 3.1. The Chronic Care Model¹

Rothman and colleagues (2003) state that improving chronic illness care is most effective in primary care settings where the majority of chronic disease patients are receiving care.

Changes to an organization aimed at improving chronic care needs to be multidimensional, including system level and patient level changes (Rothman et al., 2003). The following Table 3.1, adapted from Wagner et al., 1999, outlines the framework components and suggested improvements for health system improvements. A column has been added to demonstrate how data collection, through all phases of the thesis, will provide information for the framework components.

¹ See Appendix A for permission to use CCM image in thesis

Table 3.1. Components of the Chronic Care Model (Rothman et al., 2003; Barr et al., 2003)

FRAMEWORK COMPONENTS	EXAMPLE	METHODS USED TO OBTAIN INFORMATION
ORGANIZATION OF HEALTH CARE <ul style="list-style-type: none"> • Self-Management Support • Decision Support • Delivery System Design • Clinical Information Systems 	<ul style="list-style-type: none"> • Patients have central role in managing their own care; educational resources available • Support for improvements provided by manager • Clearly defined roles of health care team • Identification of individuals requiring proactive care 	<ul style="list-style-type: none"> • Focus groups to identify services suitable for older adults by level of risk • Survey to understand Provider Attributes in Primary Care • Interviews with patients; primary care and community care providers
COMMUNITY <ul style="list-style-type: none"> • Resources And Policies 	<ul style="list-style-type: none"> • Identification of programs in community • Appropriate referrals to community services 	<ul style="list-style-type: none"> • Focus group with providers to identify services in the community
PRODUCTIVE INTERACTIONS <ul style="list-style-type: none"> • Patient • Health Care Team 	<ul style="list-style-type: none"> • Informed Patient – confidence and skills to manage their own care; involved in care planning • Proactive health care providers – assessment of patient, appropriate supports; must have necessary expertise, information and resources 	<ul style="list-style-type: none"> • Individual interviews with Patients and Providers • Collection of screening tool and referrals

The Chronic Care Model will guide the development and implementation of care coordination processes for older adults in primary care, using the methods above.

3.2.2 Implementation Framework

A multi-level framework helps to guide the work on implementation of health innovations, developed by Chaudoir and colleagues (2013). Built on the work of Damschroder and colleagues (2009) [Consolidated Framework for Implementation Research (CFIR)], Chaudoir recognized the need to include a patient-level factor (Chaudoir et al., 2013). The CFIR is a widely used framework to support implementation of health services; including support for the implementation of the components of the CCM (Damschroder et al., 2009).

Figure 3.2 depicts the framework, which includes five categories to consider when implementing health innovations: environmental factors, organizational factors, patient factors, provider factors, and program-related to factors.

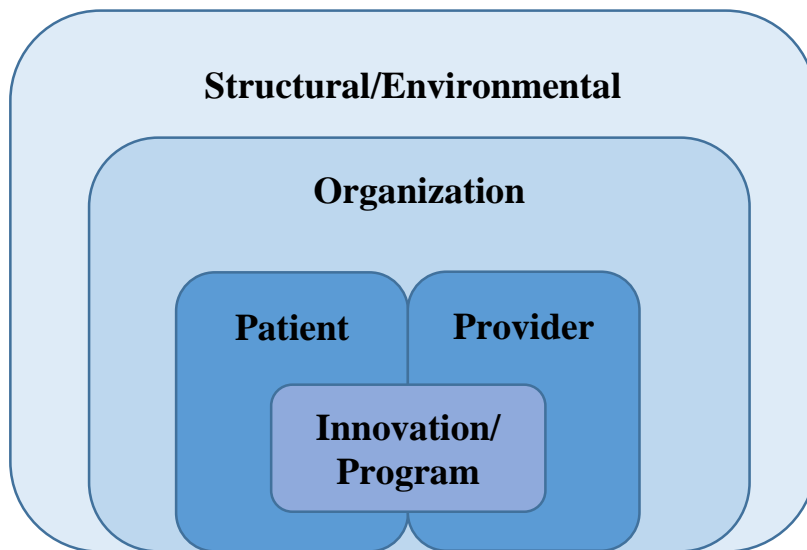


Figure 3.2. Multi-Level Implementation Framework

Structural/environmental factors include the larger context in which the organization is situated including the physical environment, public policies or infrastructure. Organizational-level factors refer to aspects of the organization including type of leadership or culture. The

provider level refers to any individual provider who has contact with the patient through the implementation of the innovation; this can include physicians, nurses, or other allied health professionals. Provider-level factors include provider attitudes towards the innovation. The patient-level factors refer to the characteristics of the patients that can influence the health innovation (program) such as participation, or attitude towards the program. Lastly, the innovation (program) level factors represent what is being implemented.

Specific attention to these five categories were made during the implementation phase (Chapter 5) to assist in identifying key factors of risk-stratified care coordination that could guide implementation in other settings. Specifically, Table 3.2 outlines the methods used to address each of the levels.

Table 3.2. Components of the Implementation Framework and Associated Methods

COMPONENT	EXAMPLE	METHOD USED TO OBTAIN INFORMATION
SYSTEM	Public Policy/Infrastructure	Focus group with providers (phase one); project advisory group with system level representatives
ORGANIZATION	Funding Model; Management Style	Site meetings; informal feedback from manager; observation of workflow
PROGRAM	Innovation being implemented	Developmental evaluation process to implement screening and referral mechanism
PROVIDER	Attitudes towards program	Informal feedback and meetings with health care providers
PATIENT	Characteristics that may influence program	Process was reviewed by Seniors Helping as Research Partners (SHARP) group

3.3 Answering the Research Question

In answering the research question, this study addresses the current knowledge gap regarding the lack of a risk-stratified approach to care coordination for older adults in primary care. By obtaining the experiences of patients, family care givers, and health care providers we better understand appropriate strategies for coordinating care. A mixed methods design within a developmental evaluation approach allows for the use of multiple data sources, collected in an ongoing iterative process, in order to develop guidelines for effective care coordination.

3.4 Research Design

Within the developmental evaluation framework, a mixed method design was used to answer the research question.

3.4.1 Developmental Evaluation

Complexity science is the study of systems that are characterized by nonlinear and emergent properties (McDaniel & Driebe, 2011). A health system is a large and complex network of organizations, programs, and people who aim to promote, restore or maintain health for individuals (Martinez-Garcia & Hernandez-Lemus, 2013). These many intertwined components result in a system that is complex in nature, and which cannot be understood as a collection of simple, individual components (Martinez-Garcia & Hernandez-Lemus, 2013). The health care system can be thought of as a complex system and when transforming components of the current health care system, it is important to keep in mind the effect it will have on all associated and linked systems. Complexity science implies that more attention needs to be placed on the quality of the relationships rather than the individual agents. The system is multidimensional and a shift in thinking from single processes towards thinking in

patterns, interrelated processes and relationships needs to occur (Stroebe et al., 2005). When changes or interventions are introduced in the health care system, a series of evaluations may be needed to determine their impact.

When health programs and systems are viewed through a complexity lens, a *developmental evaluation* (DE) approach can allow the evaluator to conduct ongoing research as health care systems and programs change and adapt (Patton, 1994; 2011). Patton defines DE as “*processes and activities that support program/organizational development. The evaluator becomes part of the team to conceptualize, design, and test new approaches in a long-term, on-going process of continuous improvement, adaptation, and intentional change*” (Patton, 1994, pg.317). The development and refinement of the process of care coordination is thus guided by active, ongoing engagement with the primary care team, patients and family members. This approach is consistent with the Medical Research Council (MRC) guidelines for developing and evaluating complex interventions, which suggests that developmental work should take place prior to formal program evaluation (Craig et al., 2008). The MRC document provides guidelines for developing, evaluating, and implementing complex interventions to improve health.

The purpose of DE is to develop or test an intervention in a specific situation, in this case the ongoing development of a new program or strategy (mechanisms for care coordination) in a complex system (health system). Formal feedback (Chapter 6) and informal feedback (Chapter 5) were obtained throughout the project and influenced the development and implementation process. The overall project will follow a developmental evaluation approach with a particular emphasis on patient, family caregiver and provider experiences during data gathering (Chapter 6) to inform recommendations for achieving a system of coordinated care for older adults in primary care.

3.4.2 Mixed Methods Design

Concurrent Transformative Design

This research project was guided by a concurrent transformative design within a mixed methods approach (Creswell et al., 2003). A transformative paradigm involves ongoing data collection that encourages using the information to make changes to the program. Specific to this design is the use of a conceptual framework to guide the research. Qualitative and quantitative data are collected during the same data collection period and may have equal or unequal priorities. For the purposes of this project, the qualitative data provided more in-depth analysis of the patient and provider experiences during the implementation and evaluation process. The integration of the qualitative and quantitative data can occur during both the interpretation and analysis phases (Creswell et al., 2003).

Qualitative Component

Theoretical Positioning

This thesis project followed a qualitative methodology which is “designed to describe and interpret the experiences of research participants in a context-specific setting” (Ponterotto, 2005, p.128). Initially, it is important to state the theoretical positioning in which the research is being conducted. A social constructivist stance was taken throughout the research project where an emphasis was placed on understanding the participants’ experiences and where the reality was co-constructed with the participants (Ponterotto, 2005). It is believed that multiple constructed realities exist, rather than one single reality, and this is influenced by the situation, experience, perceptions and interaction between the participant and the researcher (Ponterotto, 2005). Findings were constructed jointly between the researcher and the

participants through the interview questions, as well as subsequent information arising through conversational dialogue and observation. An interview guide was developed to guide the conversations, and to allow the researcher to begin to understand an experience from listening to the words of people who live it day to day (Schwandt, 1994).

Ethnographic Approach

Consistent with the in-depth understandings of a context needed for a developmental evaluation, this study was also guided by established principles for ethnographic research (Morse, 1994; Roper & Shapira, 2000). Ethnography can be defined in various ways, but at minimum, it refers to research that has emphasis on understanding the experiences of a certain group of people (Hammersley & Atkinson, 1995). Ethnography usually occurs with a small-scale group over a longer period of time, looking to understand, describe and explain the particular case that is being studied (Hammersley, 1992). Ethnography research usually has the following features; a strong emphasis on exploring particular phenomena, investigation of a small number of cases, and involves analysis of data that is in the form of verbal explanations (Atkinson and Hammersley, 1995). This approach allowed the researcher to use in-depth interviews, participant observation of interactions, and an examination of documents to study care coordination for older adults in primary care. It is widely noted that the fieldwork and observation phase of ethnography is very important (Morse, 1994). Ethnography research allowed the researcher to present the work in a descriptive or interpretive way, which is heavily based on the researcher “being there” (Van Maanen, 2004).

The qualitative investigation allowed for detailed examination of dynamic processes that occur in the care settings, as well as the perspectives, challenges, facilitators and questions that are important to patients, their caregivers and formal health care providers.

Developing Interview Guides

Interview guides were created to include a range of questions regarding the coordination of care, referral processes, engagement of patients, and experiences of patients, caregivers, and health care providers. Six interview guides were created: 1) community care provider focus group guide; 2) health care provider interview guide; 3) patient focus group guide; 4) patient individual interview guide; 5) family caregiver individual interview guide; and 6) health care provider individual interview guide (See Appendices B-G).

Quantitative Components

Quantitative methods provided additional information about the development and implementation of a risk-stratified care coordination process in primary care. A provider survey, developed by stakeholders in partnership with the Canadian Institute for Health Information (CIHI), was used to understand team functioning before and after implementation of the screening and referral mechanisms. The CIHI provider survey considered health care provider roles, responsibilities, skills, satisfaction, collaboration and team functioning, and coordination with other services and providers.

The CIHI Provider Survey was developed by a Pan-Canadian review panel of health care providers. Priority indicators were identified through consensus workshops, consultations and a literature review. Indicators most relevant for policy makers were also included. The survey was cognitively validated in both French and English through 12 interviews with primary care physicians and nurses, questions were modified accordingly (Johnston & Burge, 2013)

In partnership with the primary care teams, a risk screening tool was implemented into the primary care settings and stratified people based on levels of need (service needs). Health

care providers completed the tool using a paper based copy which was collected for further analysis. A referral mechanism was also implemented into primary care. An online form tracked referrals and use of community services. The tracking forms provide information on the care journey experienced by some patients.

Figure 3.3 illustrates the research process including the research question, conceptual framework, and methodological design.

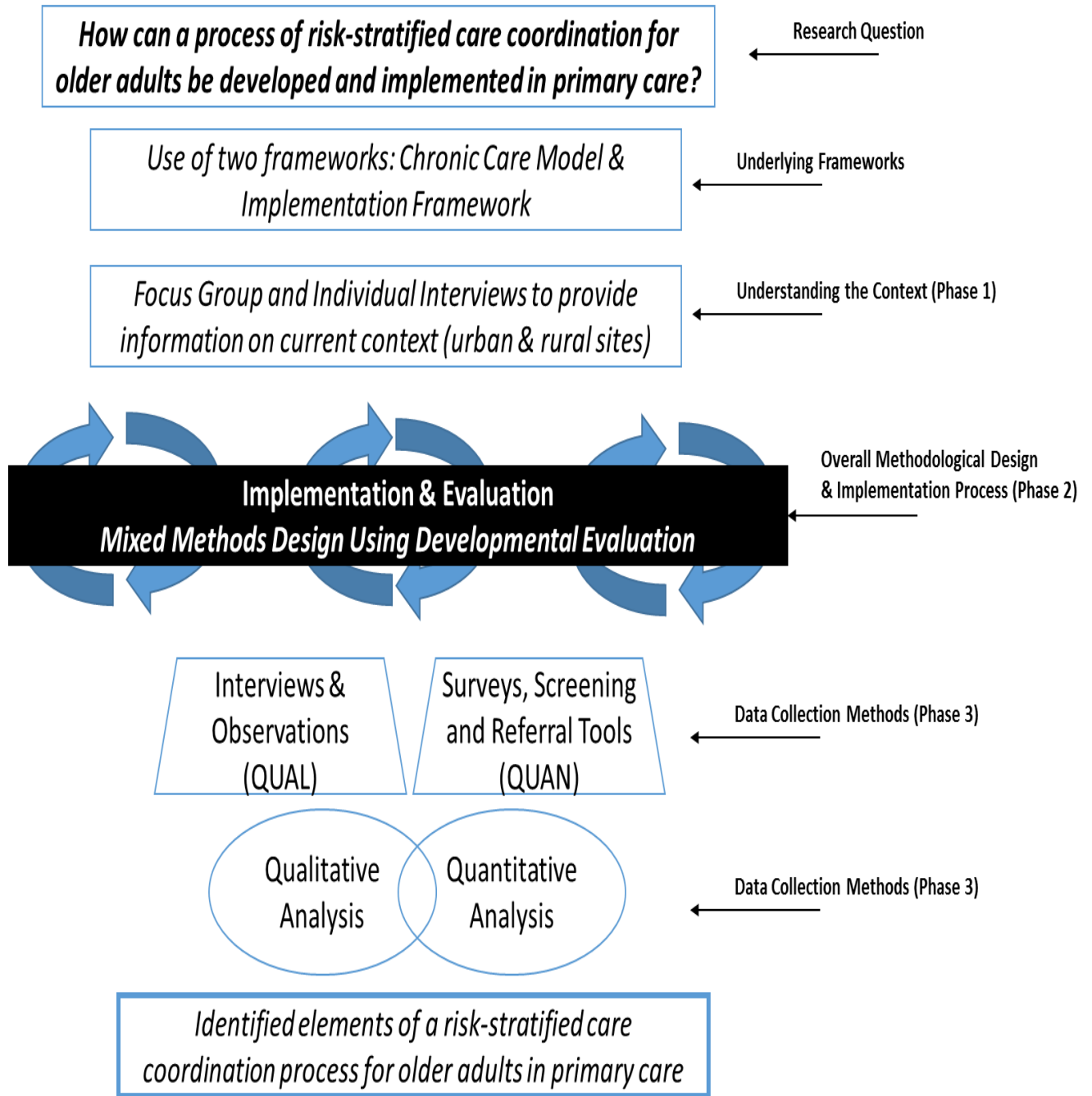


Figure 3.3. Research Process and Project Outline

3.5 Study Sites

The research project was conducted in two primary care settings, specifically Family Health Teams (FHTs) in Ontario, where strategies were developed and implemented to assess and manage older adults with chronic disease. A FHT model of primary health care was chosen for this project because of the team-based approach to coordinating care for patients. **Rural Study Site:** The Rural FHT is comprised of physicians, primary care nurses, nurse practitioners, a medical secretary, patient care coordinator, pharmacist, nurse clinicians, lab technicians, registered dietitians, health counsellors, and administrative staff. The rural site has ~ 12,500 rostered patients, 20% aged 65+ years and 8% aged 75+ years. **Urban Study Site:** The urban site is made up of family physicians, nurses, nurse practitioners, clinical pharmacist, social workers, registered dietitians, respiratory therapists, and administrative staff. The urban site has 24,000 rostered patients, 10% aged 65+ years, and 4% aged 75+ years.

3.6 Sample and Recruitment

All health care providers in the team were informed of the study (see Appendix H for Letter of Information and Consent Form). A site meeting took place at the beginning of the study to provide more information about the research project to the study sites. An information letter outlining the purpose of the study, expectations, benefits and risks were reviewed with potential health care provider participants prior to obtaining consent. Not all providers needed to participate in interviews and were not pressured to participate. A note was made of those who do not wish to participate, and therefore no observations occurred when they were present. A sample of 6-8 health care providers were purposively sampled at each FHT site. Providers who were participating in the implementation of the care coordination processes were

approached to obtain a variety of perspectives (physicians, nurses, allied health professionals) and to generate adequate information to satisfy an ethnographic approach (Morse, 1994).

A primary care provider served as a “gatekeeper”. A gatekeeper is an individual or group who serves as an “internal contact for the researcher” in order to direct the researcher to suitable and willing participants (see Appendix I for script). The ‘gatekeeper’ informed patients about the study and requested permission for the researcher to speak with them. Participants were approached at the clinic by the gatekeeper, following their physician visit and a letter of information was provided and consent obtained before moving forward (Appendix J). Older adults who represented different levels of risk (identified by the risk stratification tool) were sampled, using a stratified purposeful sampling technique where individuals are sampled from different health care settings (urban and rural) and by risk level. A total of 4-6 patients at each site should be adequate to provide information sufficient for an ethnographic study (Morse, 1994); however only 2 participants were recruited from the rural site.

Caregivers were also recruited to share experiences (see Appendix K for Letter of Information and Consent Form). Permission to contact caregivers was obtained from patients before connecting with the caregiver.

Inclusion criteria for the study sample included the following: a) Health care providers: any provider at either site who is willing to participate in interviews (individual and focus group) and observations; b) Patients: Participants must be 65+ years and they must be a rostered patient at one of the two study sites; c) Caregivers: The patient must give permission for their caregiver to be contacted and involved in the research project.

Saturation is reached when no new information arises during interviews.

3.7 Study Plan Overview

The following section provides data collection details. The qualitative data collection includes ethnographic observation, field notes, focus group and individual interviews which provides an in-depth understanding of experiences and processes. Quantitative data collection includes surveys, and screening and referral forms. Together, these data sources provide information on the experiences of participants which gives insight into different perspectives around care coordination for older adults.

3.7.1 Phase 1: Understanding the Context (Chapter 4)

(Providing information for Sub-Questions #1)

During this phase, the aim was to understand current referral processes between primary care and community care organizations, services offered by community organizations, and facilitators and barriers to care coordination.

In-depth, semi-structured, focus group interviews were completed with primary care providers from the study sites and with community care providers, separately. Focus group interviews were held during the first month of the research project, one with each primary care team, and one with community care providers located around the primary care boundaries of each team. Participants (n=6-8/group) took part in the interview which lasted ~60 minutes in length (Krueger & Casey, 2000). Individual interviews (n=7) were also conducted with those that could not attend the focus group interviews. The interview was be recorded and transcribed verbatim.

The data collected informed the development and implementation of mechanisms to improve care coordination for older adults in primary care.

CIHI Provider Survey (Sub-Question #5): The CIHI provider survey was distributed at the beginning of the project as a baseline measure of team functioning. All health care providers at each site were asked to complete the survey and put it in an envelope with the Executive Director when finished.

3.7.2 Phase 2: Implementation Process (Chapter 5)

(Providing information for Sub-Question #2)

A developmental evaluation approach was used to develop and implement a process of improved care coordination using a screening and referral process. The Implementation Framework of Chaudoir and colleagues (2013) was used to guide the implementation. Elements of an improved care coordination process were identified through a collaborative and iterative process with primary care teams.

Iterative Process with Care Providers: Aligning with developmental evaluation approaches, informal feedback was gathered from primary care health care providers. This information was documented and assisted with the ongoing development and refinement of the care coordination process.

Screening Tool and Pathways: Meetings with primary care teams provided information on how the screening tool would be implemented, who would be administering the tool, and how referrals were going to be made. The tool is consistent with the findings from O’Caoimh and colleagues (2015) which state that a short instrument covering age, activities of daily living, caregiver availability, self-reported health and recent health care utilization is necessary for risk-prediction of older community-dwelling individuals.

Referral Process: Information gathered from the focus group interviews in phase one helped to provide information about service utilization for older adults. This information was used to create pathways for older adults based on level of risk and a referral process was implemented into primary care.

Seniors Helping as Research Partners (SHARP): Input from older adults and their caregivers is a valued component of any research project geared towards improving care. In 2013, the *Geriatric Health Systems (GHS) Research group* launched SHARP, which is a group that includes more than 60 older adults from the Waterloo Wellington community (www.uwaterloo.ca/ghs/SHARP). This network is made up of individuals with diverse backgrounds, experiences, and health statuses. A collaborative partnership has been built and members will be considered partners throughout the research project. A focus group interview was conducted to understand their views on implementing a screening and referral process into primary care.

3.7.3 Phase 3: Evaluation (Chapter 6)

The final phase of the project aimed to understand patient and provider experiences with the screening and process that was implemented in the previous phase. Screening and referral information were collected from each study site along with the following data:

CIHI Provider Survey (Sub-Question #5):

At the end of study, the health care providers completed the CIHI provider survey again for follow up data. . All health care providers at each site were asked to complete the survey and put it in an envelope with the Executive Director when finished.

Screening and Referral Tools (sub-question #3): Data from the screening and referral process were collected by the researcher every two weeks. This information was used to

understand the number of individuals being screened at different risk levels, and the resulting referrals that were made.

Provider Experiences (Providing information for sub-question #3): Health care providers underwent training on the risk screening tool and referral mechanisms (in phase 2). Following the implementation of the tools, in-depth, semi-structured, face-to-face interviews were completed with health care providers to capture individual perspectives. Interviews were recorded, lasting ~60 minutes in length, and were transcribed following the interview. A sample of health care providers were interviewed from each site including, clinical nurses, and allied health professionals.

Patient and Caregiver Experiences (providing information for sub-question #4): All patients (70 + years) underwent the screening as part of routine care when they attended the FHT. A clinical nurse administered the tool, recorded the score, and worked with the patients, and caregiver (if present) to develop a referral plan.

In-depth, semi-structured, face-to-face interviews were completed with patients and families to capture individual perspectives. Two interviews were completed with each patient and family caregiver (if available). The first interview was conducted in the clinic or at the patients' home with a few days of the tool being administered. The second interview took place two months later to assess subsequent experiences. Specific attention was placed on the feelings of engagement in care decision-making and thoughts about the process of care coordination.

Ethnographic Observation and Field Notes (sub-questions #3 and #4): Observation occurred before, during, and after interviews. Observations allow for validation and

interpretation of information provided by participants during interviews (Morse, 1994; Hammersley & Atkinson, 1995). Field notes were written when observations and interviews are completed (Appendix L). The field journal used a structured format based on recommendations for ethnographic research (Hammersley & Atkinson, 1995; Lincoln & Guba, 1985). Entries were dated, and began with a narrative of what was observed and heard. The field notes include as much detail as can be recalled and personal impressions, emerging interpretations, and concerns were documented.

3.8 Data Analysis Plan

Coding, Theming and Interpreting the Data: The data was analyzed using emergent coding techniques (Lofland et al., 2006) where the perspectives of the patients, their caregivers and the primary care teams were considered. Data analysis for research conducted with an ethnographic approach is an iterative, ongoing approach that influences the course of the research. Focus group and individual interviews, screening and referral documents, observations and field notes make up the material necessary for thorough data analysis. Based on the analysis techniques identified by Lofland and colleagues (2006), line-by-line reading of the text occurred. Initial coding of themes was followed by focused coding of patterns and interesting concepts, with analyses conducted in NVivo 10 (QSR, 2010). When the coding was complete, a clustering technique was completed to group codes into *themes* (Lofland et al., 2006; Conklin et al., 2011; Braun & Clarke, 2006). Each cluster has a name, brief description, illustrative quotations from the data, and a list of codes that support the theme.

Quantitative: Analysis of survey results and tracking forms were done using SPSS version 22.0 (IBM Corp, 2013). The CIHI provider surveys was collected and analyzed at the

beginning of the project providing data on the current state of the organization. The survey was also completed at the end of the project. The provider survey included questions with both categorical and continuous response options. Descriptive statistics include frequencies, means and standard deviations. Pre and post comparisons were completed using unpaired t-test statistics.

Screening forms for each participant and associated care pathway were also analyzed. Descriptive results are presented in Chapter 6. This provides information on the number of people screened at each risk level, and the associated referral that took place.

Ensuring Methodological Rigour

To promote trustworthiness of the findings, the following criteria was followed: credibility, dependability, confirmability, and transferability (Lincoln & Guba, 1985). *Credibility* included member checking (i.e. sharing categories and interpretations with participants to determine if their realities are adequately represented) and peer debriefing. *Dependability* was established through triangulation of data collection methods, sources, and informants. *Confirmability* was achieved through an audit trail that enables another researcher to follow and understand the steps taken in the study (Sandelowski, 1986). And lastly, *transferability* was established through “thick description” of findings for each site to assess the feasibility of transferring the findings to other contexts.

Ethical Considerations

Ethics clearance for this project has been granted by the University of Waterloo Research Ethics Board (ORE #20452; Appendix O). All participants signed an informed consent form prior to the interviews. To ensure confidentiality throughout the study,

participants were given pseudonyms and all the identifying information was removed from the collected data. All participant information related to the study has been kept in a secure location, on a password encrypted hard drive.

4.0 UNDERSTANDING THE CURRENT CONTEXT: COORDINATING CARE FOR OLDER ADULTS IN PRIMARY CARE SETTINGS

Abstract

BACKGROUND

It is well known that older adults are high users of the health care system. Primary care could play a stronger role in coordinating care for older adults, but at the present time is poorly positioned to do so. Older adults with chronic conditions receive care from multiple providers, across multiple settings, and this care is often unorganized and confusing. In 2005, Ontario established a model of interprofessional primary care (Family Health Teams) with the aim of providing enhanced interdisciplinary care to patients. However, there is still a need for primary care improvement. These improvements should be informed by an in-depth understanding of the current operations of primary care teams, including their relationships with other community services. The aim of this study is to develop an understanding of the current operations, including the current referral process and current state of information sharing, and the context of two family health teams in Ontario. This information will be used to develop and evaluate better care coordination processes in primary care.

METHODS

Focus group and individual, semi-structured interviews with 30 health care providers were conducted. Purposeful sampling was used to ensure information was provided from different professional perspectives. Interviews were audio-recorded and transcribed verbatim. Using NVivo 10 (QSR, 2012), data were analyzed using thematic analysis using Lofland and colleagues' (2006) line by line coding techniques. A cluster technique was then applied to group similar codes into themes.

RESULTS

In total, three focus group interviews (involving 4-6 health care providers/focus group) and six individual interviews were conducted with health care providers from two primary care teams and community care organizations. Six key themes were identified: 1) Challenges engaging older adults in decisions about their care; 2) Who is responsible for coordinating the care? 3) Fragmented information sharing between health care providers; 4) Lack of standardized referral processes and follow-up; 5) Identifying services in the community for older adults; and 6) Caring for older adults in rural communities.

DISCUSSION

The results of this study provided an in-depth understanding of the current context in which the primary care teams are currently operating. Improved primary care will require stronger processes of coordination, and greater knowledge of and connections with other community services. This information provides a helpful basis for implementing interventions in primary care.

4.1 Background

Older adults use a large amount of health care services, however the current health care system is not well designed to meet their needs. Primary health care is seen as being the health care system “first point of contact” and as the patient’s medical “home”, helping patients navigate and coordinate their care journey (Starfield et al., 2005; Bodenheimer, 2008). In Canada, primary care is defined as, “*a service at the entrance to the healthcare system. It addresses diagnosis, ongoing treatment and the management of health conditions as well as health promotion and disease and injury prevention. Primary care is responsible for coordinating the care of patients and integrating their care with the rest of the health system by enabling access to other health care providers and services*” (Kingston-Riechers et al., 2010). Effective primary health care also provides continuing care for chronic conditions and involves a wide range of health care providers in the care provided to patients (Health Council of Canada, 2005; Canadian Institute for Health Information, 2006).

Although primary health care seems like the best place within the system to provide and coordinate care for older adults, it is poorly positioned to do so. Through the development of both structural and funding-based barriers between primary and community care, the delivery of healthcare has become fragmented in many countries (Glasby et al., 2006; Banfield et al., 2014). Many patients, particularly those individuals who are older and who experience one or more chronic conditions, may require long-term, often complex care from multiple providers working in a variety of settings (Van Houdt et al., 2013; Robben et al., 2012). The delivery of seamless integrated care by multiple professionals across a variety of settings to individuals who may be experiencing multiple chronic conditions, may be limited by the context in which primary care is currently located (Robben et al., 2012). Recognition of the

limitations placed on continuity of care by fragmented service delivery has led to the investigation of new models of care delivery in primary care. These include care coordination strategies to facilitate care across settings, institutions, organizations or professionals, in order to improve support for patients with chronic health conditions (Robben et al., 2012; Notle et al., 2012). Care coordination has been defined as “*the deliberate integration of patient care activities between two or more participants involved in a patient’s care to facilitate the appropriate delivery of health care services*” (Bodenheimer, 2008). This notion of deliberate integration extends not only to provider-provider interactions, but also includes the sharing of accurate and appropriate information and effective collaboration among professionals, patients, their families and informal carers (Robben et al., 2012; Bodenheimer, 2008).

There is a recognition that primary care needs to move away from a focus on episodic care in which the majority of patients seek attention for specific, acute complaints and leave care when treatment has been received (Sevin et al., 2009). Increasingly, health care providers are acknowledging the need to work with the patients, their families, and informal caregivers, and to collaborate with other health care providers to tailor healthcare to better fit the individual patient context (Sevin et al., 2009). It is said that models of primary care are evolving to become more patient-centred and more collaborative (Van Houdt et al., 2013; Sevin et al., 2009) and the delivery of *seamless integrated* care has become a central concept in the ongoing development of primary care models (Boeckxstaens et al., 2011). Care coordination has become one of the key components of patient-centred primary healthcare, particularly in the area of chronic disease management. Patients with multiple chronic conditions view well-coordinated care as a means to receive care that is focused on their individual goals and priorities while other stakeholders see it as a way to improve system level

outcomes in terms of efficient service delivery, reduction of unnecessary utilization and cost control (Bayliss et al., 2014).

Furthermore, family physicians are often considered to be the structural link for coordination between primary, community and hospital care for the patient (Van Houdt et al., 2013). Family physicians are viewed as the central medical professional in the care and management of chronic disease, in particular; in part, this is due to their longstanding relationship with the patient which allows them to take a broader view that takes into account a longer term medical history and greater knowledge of the individual patient context (Boeckxstaens et al., 2009). However, most family physicians are not in a position to take on the duties of a full-time care coordinator. The demands of caring for patients with chronic conditions represents a substantial increase to physician workload (Sevin et al., 2009). Some primary health care practices have added or reorganized staff and delegated the work of coordination, creating a “care team”, who all participate actively in meeting the needs of an individual patient (Sevin et al., 2009). The idea of primary care “teams” was established in the Ontario health care context through the launch of Family Health Teams (FHTs) in 2005. FHTs are comprised of physicians, nurses and interdisciplinary care providers such as; social workers, dieticians, or occupational therapists, who provide services such as chronic disease management, counseling, education, and palliative care (Sweetman & Buckley, 2014). There are currently 187 FHTs in Ontario. The use of care teams is said to improve efficiency, staff satisfaction, and the patient experience of care (Sevin et al., 2009). Although FHTs were established almost a decade ago, care is still disjointed between primary and community care in Ontario (Sweetman & Buckley, 2014).

This study aims to understand the current context and operation of primary health care teams, focusing on the current process for referring older adults to community care services from primary care; the current state of information sharing; and general information about the services available to older adults in the community. This information will become the basis for the next two phases of the research project - , implementation and evaluation - aimed at improving primary care processes of care coordination for older adults.

4.2 Methods

This study uses qualitative methods (focus group and individual interviews) and thematic analysis of the data to understand the current referral and care coordination process between primary care and community care in two primary care locations, a rural and an urban site. Quantitative data were collected to describe current study site characteristics.

4.2.1 Sampling and Recruitment

Purposeful sampling was chosen as the recruitment approach and was completed between January 2015 and April 2015. It was important to gather the perspectives of persons who might play a role in coordinating care for older persons (e.g. nurse, social worker, care coordinator). Two primary care sites were chosen and the community care organizations, serving seniors, working around that site were noted. It was also important to involve community care providers - those individuals who work outside of the primary care centre but receive referrals from the primary care centre. These could include community care coordinator, Alzheimer Society program directors, and care providers for community services such as nutrition services (e.g. Meals on Wheels) or transportation. Individuals were recruited through standardized email communication and participants were asked if they felt anyone else

should be involved and contacted. Connections made through the local Geriatric Services Network (regional geriatric care planning and coordination body) helped to facilitate the list of people to be contacted.

The target sample size for this phase of the study was approximately 6-8 individuals for each focus group, following common qualitative procedures (Krueger & Casey, 2000). Primary care provider and community care provider focus groups were kept homogenous as per common focus group approaches (Krueger & Casey, 2000).

4.2.2 Data Collection

Qualitative Data: Focus group and individual interviews were conducted with primary care and community care providers. Interviews were conducted at two study sites, one representing a rural community and one an urban community. Focus group interviews were conducted with three groups: urban primary care team, urban community care representatives, rural community care representatives. Individual interviews were conducted with participants who could not attend focus group interviews, including rural primary care team providers. Focus group and individual interviews were conducted face-to-face or by telephone. Focus group and individual interviews were 60-90 minutes in length; these were audio-recorded and transcribed verbatim. In order to guide and assist the interviewer, an interview guide was created with questions that would enable the researcher to gain a better understanding of the current referral process, communication mechanisms, and information on how providers currently engage patients in care planning. This interview guide can be found in Appendix C.

Quantitative Data: To obtain a better sense of the interprofessional team context, the Canadian Institute for Health Information (CIHI) Attributes of Primary Care: Provider Survey (2013)

was distributed to primary care providers at each study site. The survey considers health care provider roles, responsibilities, skills, satisfaction, collaboration and team functioning, and coordination with other services and providers. Providers (nurses, physicians, pharmacists, etc.) were asked to complete the survey and place it in an envelope in the Executive Director's office. Surveys were completed anonymously.

The CIHI Provider Survey was developed by a Pan-Canadian review panel of health care providers. Priority indicators were identified through consensus workshops, consultations and a literature review. Indicators most relevant for policy makers were also included. The survey was cognitively validated in both French and English through 12 interviews with primary care physicians and nurses, questions were modified accordingly (Johnston & Burge, 2013)

4.2.3 Data Analysis:

Qualitative data collected during the interviews consisted of verbatim transcripts for each focus group and individual interview. Transcription was completed by the author and other students on the research team. Each transcript was checked against the original recording for accuracy and re-read to remove identifying information. Transcripts were uploaded into the qualitative analysis software, NVivo 10 (QSR International, 2010). All interview data were analyzed using line by line coding as outlined by Lofland and colleagues (2006). According to Lofland and colleagues, initial coding was followed by focused coding where patterns, themes, and interesting concepts were identified. A *clustering technique* was completed, where similar codes were grouped into *themes* (Lofland et al., 2006). Each cluster was given a name and brief description, with quotations from the data to support the theme.

Quantitative Analysis: The surveys were collected from each study site and data were entered

into SPSS 22 (IBM Corp., 2014). Data were analyzed to provide a descriptive characterization of the providers at each site, as well as the current state of primary health care team practice, including team function, provider satisfaction, and other dimensions. The provider survey includes questions with both categorical and continuous response options. Descriptive statistics included frequencies, means and standard deviations.

Ethical Considerations:

Ethics clearance for this study was obtained from the University of Waterloo's Office of Research Ethics. Prior to each interview, participants were briefed about the purpose of the study, the presence of the digital recorder, and the right to withdraw participation or data at any time. All participants were notified of the confidentiality and anonymity of their responses. Real names have been replaced by pseudonyms.

4.3 Results

4.3.1 Qualitative Results

Three focus group interviews were completed with 4-8 participants in each group and six participants were interviewed individually (n=30 participants in total). Table 4.1 describes the gender, role and location of each participant. In total, representation from the rural community included six participants from primary care, six from community care, and two hospital representatives. Representation from the urban area included nine participants from primary care, six from community care², and one hospital representative. Community care providers represented organizations providing care including both community support services and home care services.

² Note: Only community services that focus on care for the senior population were included

Table 4.1 Participant Description

Provider Role	Gender	Site/Location
Case Manager	F	Primary Care Rural
Care and Service Manager	F	Rural Community
Care Coordinator	F	Rural Community
Geriatric Emergency Management (GEM) Nurse	F	Rural Hospital
Geriatric Emergency Management (GEM) Nurse	F	Rural Hospital
Outreach Program Coordinator	F	Primary Care Rural
Nurse	F	Primary Care Rural
Nurse	F	Primary Care Rural
Occupational Therapist	F	Primary Care Rural
Program Coordinator – Community Centre	F	Rural Community
Nurse Clinician/Diabetes Educator	F	Primary Care Rural
Director – Community Services	F	Rural Community
Nurse	F	Primary Care Urban
Medical Office Assistant	F	Primary Care Urban
Director	F	Primary Care Urban
Nurse	F	Primary Care Urban
Physician	M	Primary Care Urban
Nurse	F	Primary Care Urban
Nurse	F	Primary Care Urban
Nurse	F	Primary Care Urban
Medical Office Assistant	M	Primary Care Urban

Program Director – Alzheimer Society	F	Urban Community
Manager - Community Programs	F	Urban Community
Director – Community Services	F	Urban Community
Manager – Specialized Geriatric Services	F	Urban Community
Geriatric Emergency Management (GEM) Nurse	F	Urban Hospital
Program Manager	F	Rural Community
Director – Community Health Centre	F	Rural Community
Case Manager	F	Urban Community
Director – Community Services	F	Rural/Urban Community

Most primary care providers were nurses (n=7) who would be participating in the subsequent research study; one physician from the urban site participated in the focus group interview. The community care provider roles varied including providers working in a hospital setting, directors and program managers of community organizations, and frontline case coordinators.

The findings revealed a number of themes related to the current primary and community care contexts. After reviewing the data and performing appropriate thematic analysis, six key themes emerged from over 100 codes. Table 4.2 outlines the overarching themes, and subthemes and example codes for each theme.

Table 4.2. Themes and Subthemes

THEMES	SUBTHEMES	EXAMPLE CODES
<p>1) <i>CHALLENGES IN ENGAGING OLDER ADULTS IN DECISIONS ABOUT THEIR CARE</i></p>	<ul style="list-style-type: none"> • <i>Older adults should be more engaged than they are currently</i> • <i>Understanding why older adults decline services</i> • <i>“Time” is needed for meaningful conversations</i> • <i>Caregivers are an important part of the circle of care</i> 	<ul style="list-style-type: none"> ○ Engage patients in discussions ○ Need to engage older adults ○ Patients want one point of contact ○ Need individualized care ○ Decline services to maintain dignity ○ Need time to communicate
<p>2) <i>WHO IS RESPONSIBLE FOR COORDINATING THE CARE?</i></p>	<ul style="list-style-type: none"> • <i>The role of a coordinator</i> • <i>Role clarity needed among patients and providers</i> • <i>Primary health care as a hub for coordinating care</i> 	<ul style="list-style-type: none"> ○ Role of participants ○ Falling through the cracks ○ Barriers ○ Complexity of patients
<p>3) <i>FRAGMENTED INFORMATION SHARING BETWEEN HEALTH CARE PROVIDERS</i></p>	<ul style="list-style-type: none"> • <i>Communication between primary care and community care is fragmented</i> • <i>Providers going beyond what is expected of them to get information about a client</i> • <i>Multiple documentation systems make it hard to access patient information</i> 	<ul style="list-style-type: none"> ○ Not enough patient information ○ Phone calls to get information ○ EMR issues ○ Information not shared
<p>4) <i>LACK OF STANDARDIZED REFERRAL PROCESSES AND FOLLOW-UP</i></p>	<ul style="list-style-type: none"> • <i>Types of referrals to community services</i> • <i>Issues with referring patients to external services</i> 	<ul style="list-style-type: none"> ○ Self- or Friend Referral ○ Fax referrals ○ Physician referrals ○ Services most accessed within organization by older adults
<p>5) <i>IDENTIFYING SERVICES IN THE COMMUNITY FOR OLDER ADULTS</i></p>	<ul style="list-style-type: none"> • <i>Many organizations offer a variety of services for older complex patients</i> 	<ul style="list-style-type: none"> ○ Self-management programs ○ Provider not aware of service options ○ Common referrals from primary care
<p>6) <i>CARING FOR OLDER ADULTS IN A RURAL COMMUNITIES</i></p>	<ul style="list-style-type: none"> • <i>Cultural boundaries</i> • <i>Coordinating care in large geographical location</i> 	<ul style="list-style-type: none"> ○ Complex patient in rural location ○ Rural location

CHALLENGES IN ENGAGING OLDER ADULTS IN DECISIONS ABOUT THEIR CARE

Evident throughout many of the discussions was the fact that although healthcare providers felt that engagement of patients was important in health care decision-making, it was not done as well, or as often, as it should be. Participants were asked to discuss how they currently engaged older adults and caregivers in care planning; the following provides some examples of the various responses:

Yes, we use surveys if that's what you're getting at ... there's really no participatory involvement in the care pathway or planning – Primary Care Provider Urban

Not as much as they could or should be. I think that many feel powerless – not knowing what is available to them or how to 'work the system'. - Urban Community Care Provider

Community providers felt that they offered their patients' options but it was up to the patient to decide whether to accept the service. Providers felt that they couldn't do anything if the patients declined services.

We always honor the wishes of the individual that we're working with, so we can make recommendations of services that we think would be really helpful but ultimately it's their decision of whether or not they want to access them. – Community Care Provider (Urban)

We may present all of the options and make our suggestion about what would be most helpful, but ultimately if our client does not want that service then that's up to them. – Community Care Representative (Urban)

Providers recognized that as they get to know their patients better and build a relationship, discussions are open and patients may opt to participate in services.

...as you build trust in the relationship, you can get people engaged in other services – Community Care Provider (Urban)

Community care providers also identified issues when goals and preferences are not discussed with the patient. In the case below, the physician made a referral, however when the community care provider offered the service, the patient was not willing to accept the service.

We also want to have a better idea of what their goals are, because what the goal is, let's say, for example, the goal for the family physician might be a med review by psychiatry. When we get in there we might have to do some work arounds, massaging that...and they [patient] may not be ready to say yes... So that sometimes, I think is a challenge.... – Rural Community Care

Many providers acknowledged the benefits of engaging patients and families in health care decision-making but identified the challenges that go along with those discussions. In order to engage patients in a meaningful way, there is a level of education that needs to occur for both the providers and the patients. If the patients are not aware of the services that are being offered to them, they may not see the value and therefore may decline the service.

I think it's just a hard thing to have a menu and say what would you like, when they don't really understand maybe fully what each service might bring them, so that needs to be explained when you're offering this service or getting consent for a service – Community Care Provider Rural

You have to first educate them on what's available, if that's even like possible, and then I think that you can have a conversation about, you know,

sending someone to a memory clinic versus the geriatrician or psycho-geriatrician or versus having an outreach team come to their house versus going to the clinic – Community Care

Above all, a strong and trusting relationship is most important when engaging older adults.

Building a trusting relationship takes time and the current health care system is not designed to support the time that this may take. As illustrated in the quote below, the health system also does not support the community care provider being the one touch point for the patient.

It becomes challenging when the two worlds of quality improvement and lean processing meet complex clients like this. Because it's not efficient for me to drive every day to buy a coffee to drive over to [Bob] to sit for an hour talking about his cat. It's not efficient, it's not productive per se. So for those 15 to 20 times I have to drive to sit and talk about [Bob's] cat, nothing comes out of that. But on the 21st time, I get buy-in. And then I get support for him. The other kind of caveat to that is because I try so hard and I go out of my way and I kind of bend over backwards to really focus on providing the client with that compassion and empathy that they really not ever experienced in their life, I become the person that they call for everything, which is also not efficient. – Community Care Provider (Rural)

Overall, patient engagement was recognized as important, however providers stated that a) the system does not support meaningful engagement (e.g. time with patients); b) both providers and patients need to have more time and education around the services available to older adults in the community; and c) providers need more education around relationship building. This will allow for patients to express their goals and preferences and ultimately create a care plan that suits their individualized needs.

WHO IS RESPONSIBLE FOR COORDINATING CARE?

During the focus group interviews, care coordination was discussed, including who providers felt was most responsible for coordinating care for older adults. Many participants agreed that care coordination should occur in the primary care setting where patients may have longer standing relationships with physicians and nurses. The following excerpts illustrate these views:

I think that putting that role [care coordination] in primary care could certainly have some pros

Primary care should be the hub of care – and this requires coordination. I don't think this is a new role, however. We have too many ineffective care coordinators throughout the system that are 'system-centred' rather than 'client-centred' – by that I mean that they coordinate the services that they are responsible for/connected to but no more. – Community Care Provider

The second quote also demonstrates the feelings expressed by some providers that there are already care coordinators in the system however, they work for an organization rather than working across the system to ensure a patient is connected to the right services.

Regardless of where the coordination happens, having one person to communicate with is important for the patient:

I think having one point of contact that people feel comfortable calling in to is essential. Like, you've got all of these other organizations out there, but especially our community here, being such a rural older population... they don't like having to answer to an answering machine, they like a real voice. So I think having that real voice available to them is important for that system navigation piece. You know, have someone who's going to say "Okay, this is where we need to go, and let's make it happen." – Primary Care Provider (Rural)

The role of a system navigator came up in all of the focus group discussions. The groups discussed whether there was a need for a specific designated role and where that person should be located within the system, versus having the system work collaboratively to coordinate care for an individual.

I would expect to see is that system navigation is part of a process or function of primary care and the home team. – Community Care Provider (Urban)

I think that what might be more advantageous is to look at our ways of communicating with each other and the systems of support we have in place for each other, and again, that it might be better done as a partnership. It's not just that we want to say "oh, you're responsible okay here you take it", you know there might be two or three people who are just as responsible for different aspects but they need to be able to work together - Primary Care Provider (Rural)

I think that people are not knowledgeable about programs and services until they need them, and then they're in a crisis situation, and then it's not a good time to be searching for information. So if there was someone they could contact then they're not taking up primary healthcare time with a physician or NP, over something that could be dealt with by the most appropriate service provider. The second thing that we run into with our hospice and our caregiving supports is, when the family is living at a distance, they are sometimes not able to respond and help mom or dad figure things out and I think by having a system navigator that person could be followed and the right services put into place to prevent a serious fall or some other situation that people are picking up on – Primary Care Provider (Urban)

It is also important to acknowledge that some patients who have knowledge of the system and feel empowered to take a leadership role in their care may indicate that they want to be their own navigator, as described in this quote below.

In fact say that we would have some consumers that feel that they should be the navigator.

Having patients engaged in discussions would allow for the best decisions to be made for individual situations.

Trying to identify who is the most responsible person for coordinating care and that role may end up in all different places, depending upon the individual. So in some cases it might be someone in the community who has a long standing relationship with that person, in other cases it might be the CCAC³ care coordinator or perhaps if neither of those, it could be someone in primary care, but instead of having multiple people taking on, like ultimately someone has to take accountability, and it may not always be the same person

Many providers in the community felt that they were already coordinating care for older adults.

However, even these individuals see the importance of engaging primary care in discussions around patients.

Well, I guess that, see that depends on what you're asking for. Because if they have a requirement for the services that Community Care Access Centre (CCAC) does, then we're doing that kind of coordination of care piece, but having the primary care physician more engaged in those care plans would be ideal, and I don't know if that happens all the time. – Community Care Provider (Rural)

Although many agree that regardless of where the coordination role occurs, a dedicated individual should care for the patient and take on the responsibility of linking the individual to appropriate services. This raises the question of how feasible it is to dedicate one person to take on responsibility or have a role across the entire system.

³ Community Care Access Centre (CCAC): There are 14 CCACs across Ontario funded by the Local Health Integration Networks through the Ministry of Health and Long-Term Care, CCAC connects individuals to care in their home or the community.

We've thought about that... It's just whether the ministry agrees with it, right? So that's the biggest thing... It's a very important role for system navigation. I think some of the things we've put in place here... even though we don't have a dedicated person doing that, we have a few people who do that role. – Primary Care Provider (Rural)

FRAGMENTED INFORMATION SHARING AMONG HEALTH CARE PROVIDERS

When the topic of *information sharing among health care providers* arose during the focus group and individual interviews, many providers had much to say. Information sharing continues to cause challenges for providers across the entire health care system due in part to the many different electronic medical records (EMRs) being used. In the local LHIN alone, there are **13** different EMR systems used across the health care system (primary care, community care, hospitals, etc.). Many providers acknowledged this challenge in the following comments:

At this point what I think our biggest challenge is the whole lack of a common documentation system. Because I don't have access to the client's EMR, which is what doctors rely on for communication between their allied staff. So it's very difficult to have a true sense of good collaboration because, you know doctors, especially the doctors, not so much allied health professionals, but the doctors especially really just don't have the time to step away from the client to come and find me. And I may or may not be in the building. – Primary Care (Rural)

Further to that, there are no standardized forms in place for communication between primary care and community care, creating the fragmented, or often non-existent, communication between the two health sectors. Some health care providers have taken it upon themselves to come up with solutions to ensure the information is easily accessible for the physicians who do not have a lot of time to read multiple pages of a report. However, if every community care

provider had their own method of reporting, this could cause more complication for a physician who may be trying to quickly review the document, as indicated in the excerpt below from the community care provider who recognizes her method for documenting may be more “detrimental” than helpful.

Interviewer: Does anything get sent back to primary care about the patient?

many voices saying ‘no’

Care Provider: That’s what makes it really hard....

Care Provider (Urban): When three of those four pages are information about a client’s name, marital status, and disease diagnosis. So the demographic information that occupies page one is really of no use to the doctor and after looking at page one think this is bananas and skip it. You know. They don’t have time. So what I try to do is send my note, so I’ll do my home visit with the client and do my assessment and be very very thorough in putting as much detail I can about what happened when I was in the home. I really want the doctor to be able to read the note and feel like they were there. Sometimes that’s detrimental because sometimes doctors want a one sentence snapshot: Client is good, services are started, check, carry on. And when I send them this mass note that’s quite thorough, I’m not sure how many like or dislike that.

As illustrated in the excerpts below, many providers point out that information sharing among providers, within or between organizations, is an area for improvement at a system level.

We um don’t have a lot of conversation going back and forth between primary care. What does happen sometimes ... we would check on Clinical Connect⁴ to try and get more information about it which isn’t always helpful...sometimes they don’t give you all the information. Again, that’s limited too because Clinical Connect – not everybody is connected –

⁴ Clinical Connect is a secure, web-based portal that provides physicians and other health care providers with access to patients’ EMR from hospitals and community care access centres.

Community Care Provider (Urban)

I think that's an area that there's a lot of room for growth and improvement on. It is, for us, it's been more individualized, so as an example, if we know, if we've had a referral come from primary care locally and we're working very closely around the care for an individual, there's some natural systems in place to share and to communicate that back, but it really, really depends, we don't have a standard, formal process for that, we talk about how that might happen...but it's a bigger system to try to figure out how we communicate back. – Community Care Provider (Urban)

So that's maybe something within the system that is available to be improved I'm not sure. Outside of that it's much more on a case by case basis I would say, if we receive consent from the person to follow up with an agency or service, we try to make those connections where we can but it's certainly not a process that is done consistently the same way or with every person. – Community Care Provider (Urban)

I think it's absolutely an area for, room for improvement. We're finding, especially over the last few years that the complexity of our consumers are increasing. For example, we're providing services to somebody 24 hours a day, and it really would be nice to have a better relationship with the physician, we deal with the primary care physician, they say "sure your staff can do that" and then, like "no we can't do that" and if we could be on the same page it would be more helpful, so that's a little bit of a challenge. – Community Care Provider (Rural)

Ultimately, these issues affect the patient as they are required to repeat their stories multiple times to multiple health care providers. This is referred to as “assessment burnout”. Patients also lose trust in the system because they have already answered questions and don't understand why the new health care provider hasn't received that information.

I agree. I agree. Yeah, no. Because they don't like having to tell their story over and over and over again. The nice thing about here, with me doing kind of that role, is that I know everybody. And I have access to the EMR.

So if they've told the story once. I can read through it, and I don't need to ask them again. Right? So just having that peace of being able to tell it that once and that's it. – Primary Care Provider (Rural)

For providers that work within the same organization (or in rural settings), it may be more feasible to have a “quick hallway conversation” to discuss a patient. However, participants acknowledged the privacy issues surrounding those conversations. Participants also suggested that phone conversations should occur more often when a provider needs to get information about a patient.

Call anybody, it's okay to call....I've got this client right, and basically – just like what happened today... our hallway conversation: had a nurse come and say '[Provider Name], come here, I need to bounce something!' so just having that and being able to do it... I know privacy is out there and I know there's a lot of issues, but...

It is evident that this is a huge issue across the entire health care system, and not just between primary and community care.

LACK OF STANDARDIZED REFERRAL PROCESSES AND FOLLOW-UP

Another major theme that arose during the focus group and individual interview process was the current process of referring patients to community services when appropriate. The interviews revealed that there was currently no standardized process in primary care for identifying which patients would benefit from additional services.

Interviewer: Do you currently use any standardized assessments on your older adults?

Primary Care Provider (Urban): No, definitely not on every older adult. Sometimes the MoCA or screening for diabetes and hypertension. We go for the most commonly used ones

Interviewer: And what about referral pathways for those patients, would most of your assessments have a referral piece to them as well?

Primary Care Provider (Urban): Not always, no.

Care providers did discuss however, that when a patient was referred to a service, multiple modes of communication are used to make the referral including phone calls, fax, e-referrals, self-referral or referrals from friends and family,

We do get referrals over the phone on our secure voicemail and by fax from various providers, generally they're physicians, who do it that way, we also get referrals through the e-referral aspect as well – Community Care Provider

Health care organizations on the other end of the referral must keep track of the different referrals coming in through the various modes of communication. Multiple modes of communication make it challenging to track referrals and ensure patients are receiving the services they need.

In this particular health region, there is a centralized intake process for referring to specialized geriatric services. This allows a nurse who works for centralized intake to review the referral, access multiple databases of patient health information and put together a package that is sent on to the specialist. This helps to prioritize patient urgency as well provide information to the next health care provider who may not have access to all of the different EMR systems.

For some programs, there are a number of referrals made by friends and family on behalf of the patients, *Phone calls, a majority of them are clients or family members*

(*Community Care Provider*). Sometimes health care providers discuss a service with the patient and then leave it up to the patient to access the service. One Family Health Team in the rural community indicated that they generally ask patients “*how confident are you feeling that you can make that call?*” and depending on the answer, providers may help make connections for that patient. Participants noted that patients can be informed about a service, but if they do not have someone helping to make the connection or attend with them, the referral will not follow through.

Another major issue discussed by multiple health care providers (participants) was the concern around offering programs or services to patients who needed the service but did not want to accept it.

We'll go out and visit people and a referral has been made, but really they don't want the service and they don't want any involvement.... but I also think, I mean the other part that I just also want to raise, is there are some people where the referrals don't get made, and that to me is also an equally important issue. – Community Care Provider (Urban)

Participants acknowledged these issues of patients declining services or people not being referred in the first place. Community care providers spoke about how important it was to educate primary care providers on the services that are offered in the community. Primary care providers tended to know about the few services that they referred to often.

We've tried to incorporate ways to remind providers, because it's often difficult when you're dealing with five different medical issues to remember to refer them to that one program.

Referrals were made a number of different ways with no standardized method for communication, however most often referrals were made through fax.

IDENTIFYING SERVICES IN THE COMMUNITY FOR OLDER ADULTS

During the focus group discussions with primary care providers at both study sites, it was evident that more education was needed in terms of what services were available in the community for older adults. Providers seemed to be familiar with the common services such as those offered by the Alzheimer Society or the Community Care Access Centre (CCAC) but they were not familiar with programs or services that could help older adults who were not yet considered frail. One provider summarized the issue well in the following comment,

I think whoever is doing the referral or suggesting the referral, needs to be educated on services and resources and understand the system enough to say “here’s some of the options available to you” and “where would you like to start?” Because I think, you know, a care coordinator, for example, in the community, might see that there is a dementia that is starting with a client and feels that going to memory clinic might be a good option for the client, but says “but you can also see a specialist, that might be a good option too” knowing that the client is not able to access community very well, or there’s lots of other issues with the client, they may say “let’s start with outreach team, it’s a team of a care coordinator and specialized nurses that will look at your situation, do an assessment, talk to your physician about that assessment”, then maybe determine next steps, whether it’s seeing a geriatrician, so there’s always next steps. And it’s very individualized based on the client situation, so I think the person who is doing that assessment, be it the nurse, care coordinator, or family physician, is individuals deciding what might be the next steps based on what they know about the client – Community Care Provider (Rural)

In order to create care plans that are appropriate for the patient, it would be important to be familiar with a wide range of services in the community that could be of benefit to older adults. Participants were asked to list the services to which they commonly referred, these included internal programs within the Family Health Teams such as diabetes management or nutrition classes, or external programs such as memory clinics, specialists referrals, or the CCAC.

Subsequently, during the focus group discussions with community care providers, participants were asked to discuss services that their organizations offered that would be appropriate for older adults. The list generated from these discussions include transportation services, in home and community exercise programs, hearing clinics, arthritis education, meals on wheels, cooking class, friendship programs, support groups, and many more. Community care providers also identified that many of these services would be beneficial for older adults who are looking to maintain their health and independence in the community.

CARING FOR OLDER ADULTS IN A RURAL COMMUNITY

The last theme that emerged through the interviews was one related to caring for older adults in rural communities. Community care and primary care providers in the rural community discussed facilitators and challenges that they encounter when working with older adults. Within a rural community, providers talked about how “everyone knows everyone” both in terms of the patient knowing the care provider and care providers knowing each other. Both of these examples are illustrated in the excerpts below:

The difficulty is with connecting people because everyone is so busy but the personal connections are what I think makes rural Wellington work so well because everybody knows everybody. And you know that if you're stuck you can call – you have someone that you can call and ask a question... - Rural Primary Care Provider

I'm from this community and have been here for a number of years. So it makes it easier when I'm talking to these people, because they usually know me or my family. So that's a big plus...they feel comfortable that way. – Rural Primary Care Provider

One community provider also discussed the importance of building a trusting relationship with patients. It is difficult to have patient buy-in without the long-standing relationship. New providers (within the rural community or from an urban organization) will have better luck developing relationships with patients if they are connected through a provider with whom the patient already has an established relationship. This idea is further described in the two quotes below:

The only other thing I would like to add is I think rural is unique, and I think that you know that the organizations in this community work very well together, and have trusting relationships with seniors, so often it's someone from one of the core organizations in the rural townships that will then make the introduction to someone else and then the service will be accepted. –
Rural Community Care Provider

And I do think that rural people are a little bit more resilient, they're very concerned with their privacy, and the trust factor is really important, you know, I think that any kind of new role, like a system navigator might take a little longer in a rural community to build some traction with some of the seniors, but over time it would, especially if you're using the existing relationships to connect, and I know that you know that you know that, but rural is unique and I think that seniors also have a hard time calling an agency that's in the city, whereas if there is a system navigator close, they will see it as a rural service provider and someone they can call on –
Community Care Provider (Rural)

As illustrated above, older adults are concerned with their privacy, developing trust between the patient and provider is important.

One challenge encountered by rural community care providers is the large geographical area that they have to cover to provide services to older adults. Within one day, the community care provider could be driving across the rural region to see different patients.

It has been a real challenge, especially when I am one person who is working out of such a massive geography. – Rural Community Care Provider

There are also limited care providers working in the region, so it may be that there is only one provider for the specific organization across the entire rural area.

Providing care for older adults in the rural community presents some unique challenges or differences. As discussed by the participants, relationships are key to the success of providing care to older adults, especially in rural communities where trust and privacy are a concern. Relationships between the patient and provider allow for greater buy-in by the patient to accept services, and relationships between providers allow for knowing who to contact when looking for specific services or information. The strengths and challenges identified above were not present in the urban setting. Although care providers in an urban setting may build a long-standing relationship with a patient, this is not the same as “everyone knows everyone” and therefore building the relationship takes time. Furthermore, community care providers are not working across large geographical regions, rather, they are responsible for small sub-sections of the urban region.

4.3.2 Quantitative Results

Primary Care – Study Site Characteristics

In total, 24 health care providers (11 rural and 13 urban, out of: rural site n=26; urban site n=50) completed the CIHI Provider Survey between the two study sites. The CIHI Provider Survey explores *Information Technology; Quality and Safety; Accountability; Team Functioning; and Health Care Service Delivery*.

Table 4.3 and 4.4 provide demographic information of the respondents by study site.

Table 4.3. Health Care Provider Demographics - Rural

Code	Gender:	Profession:	Number of Days/Week see patients:
HCP_11	M	Physician	4.5
HCP_12	F	Registered Dietician	4
HCP_13	F	Registered Nurse	5
HCP_14	F	Registered Nurse	1.5
HCP_15	F	Nurse Practitioner	4.5
NCP_16	F	Nurse Practitioner	1
HCP_17	M	Physician	4
HCP_18	M	Pharmacist	4
HCP_19	F	Registered Nurse	1
HCP_110	F	Registered Nurse	4
HCP_111	F	Occupational Therapist	2.5

Table 4.4. Health Care Provider Demographics - Urban

Code	Gender:	Profession:	Number of Days/Week see patients:
HCP_21	M	Physician	2.5
HCP_22	F	Registered Practical Nurse	5
HCP_23	F	Registered Nurse	5
HCP_24	M	Medical Office Assistant	5
HCP_25	M	Physician	3.5
HCP_26	F	Pharmacist	4.5
HCP_27	F	Registered Nurse	5
HCP_28	F	Social Worker	3
HCP_29	F	Social Worker	4
HCP_210	F	Registered Nurse	4
HCP_211	F	Registered Nurse	2.5
HCP_212	F	Medical Office Assistant	5
HCP_213	F	Nurse Practitioner	5

M: Male; F: Female.

Rural Study Site:

Demographics: Physicians (n=2), Registered Nurses (n=4), an Occupational Therapist (n=1), a Pharmacist (n=1), a Registered Dietician (n=1) and Nurse Practitioners (n=2) all completed the CIHI Provider Survey. Among the 11 health care providers, the mean number of years of work experience was 20 (range = 5-43 years of experience), and they worked on average 3.3 days/week (range = 1 -5 days per week).

Organization & Team Functioning: All of the 11 providers (100%), who completed the survey, felt that that it was very easy or somewhat easy to use the EMR system to both document and search for information about a patient. When asked to look at the past 30 days, 36% of the respondents were unaware of whether or not their patients had received the wrong drug or dose, or had received incorrect results for diagnostic images or lab tests.

Providers felt that others in the practice understood their role within the team, and they felt they knew roles of other members on the team. However, a proportion of the team (36%) were *not satisfied* with the frequency that the team was able to meet as a group. Many providers indicated that they *were satisfied* with their freedom to make clinical decisions to meet patients' needs and satisfied with the time they have available to spend per patient. Providers were on average *not very satisfied*, or *neutral* regarding income from their clinical practice. Providers felt they are *usually able* to coordinate with services in the community to provide care for the most complex patients. When asked whether they believed they were aware of all other provider consultations and emergency room visits experienced by their patients, 5/10 providers said they were aware 40-60% of the time, and 5/10 felt they were aware 60-80% of the time (one provider didn't answer this question). On average, when

providers were asked, “*to what extent...*” are you able to communicate with other providers involved in a timely manner; do all providers care for the patient have the same information available to them; and do you collaborate with other providers to establish goals for treatment and management plans, the answer was *not really* or *to some extent*. Sixty-four percent of providers indicated that, during the past month, a patient’s medical record or relevant information were *not* available at the time of the patient’s visit and 50% of providers indicated that a patient experienced problems because care was not well coordinated across multiple sites or providers.

Urban Study Site

Demographics: Physicians (n=2), Registered Nurses (n=4), a Pharmacist (n=1), a Nurse Practitioner (n=1), Social Workers (n=2), Medical Office Assistants (n=2), and a Registered Practical Nurse (n=1) completed the CIHI Provider Survey. Among the 13 health care providers the mean years of work experience is 12 years (range = 1-44 years of experience) and they work on average 3.9 days/week (range = 2.5 -5 days per week).

Organization & Team Functioning: Of the 13 providers who completed the survey, 92% felt that that it is very easy to use the EMR system to document information about a patient; 76% felt it was very easy to search for information about a patient on the EMR system. When asked to look at the past 30 days, 76% of the respondents were unaware of whether or not their patients had received the wrong drug or dose, and 92% indicated they were unaware of whether their patient had received incorrect results for diagnostic images or lab tests.

Providers felt that others in the practice understood their role within the team, and they felt they knew roles of other members on the team. Many providers indicated that they *were*

satisfied with their freedom to make clinical decisions to meet patients' needs and satisfied with the time they have available to spend per patient. When asked to *indicate satisfaction with overall experience within practicing my profession*, 23% are very satisfied; 54% are somewhat satisfied; and the remaining 23% are neutral. Providers felt they are *occasionally or usually able* to coordinate with services in the community to provide care to for the most complex patients. When asked whether providers believe they are aware of all other provider consultations and emergency room visits experienced by their patients, 2/13 indicated 0-20% of the time; 4/13 providers said they were aware 40-60% of the time, 5/10 felt they were aware 60-80% of the time, and 1/10 indicated 80-100% of the time (one provider didn't answer this question). On average, when providers were asked, "*to what extent...*" are you able to communicate with other providers involved in a timely manner; do all providers care for the patient have the same information available to them; and do you collaborate with other providers to establish goals for treatment and management plans, the answer was *not really* or *some extent*. Sixty-four percent of providers indicated that, during the past month, a patient's medical record or relevant information was *not* available at the time of the patient's visit.

4.4 Discussion

4.4.1 Summary of Themes/Data and Discussion

The aim of this chapter was to understand the current state of primary care and the environment in which it operates, in relation to engaging patients in decision-making, referral processes and information sharing. Improved understanding was accomplished through data from in-depth focus group and individual interviews with 30 health care providers. Data

analysis yielded six key themes that allow for better understanding of the current context of primary care teams. Although many of the findings identified through the first stage of this project were not entirely unfamiliar in health care system research, these results provide greater understanding of the current issues faced by the primary health care sector (Bodenheimer, 2008; Elliott et al., 2014; Sinha, 2013; Rothman et al., 2003; McMurray et al., 2013). Furthermore, the issues were echoed by multiple participants across different professions (nurse, physician, manager, etc.) and across different health care sectors (primary care and community care).

The first theme, *challenges engaging older adults in health care decision making*, highlighted the importance of engaging older adults in care planning, however it was strongly identified that this is not what currently happens in daily practice. Previous studies have identified that caring for older adults is most effective in improving outcomes when it includes active in-person contact with patients and families (Bayliss et al., 2014). Specifically, older adults living with multiple chronic conditions emphasize the need for convenient and flexible access to their healthcare providers, clear communication of plans for their care that are specific to their individual circumstances, and support from a care coordinator who is able to help in prioritizing their needs and who can also promote continuity in their care relationships (Boeckxstaens et al., 2011; Bayliss et al., 2008). This is a great area for improvement in primary care where longstanding relationships are already developed between patients and health care providers.

The second theme, *who is responsible for coordinating care?* and the third theme, *fragmented information sharing between health care providers*, both highlighted the current challenges experienced by health care providers when coordinating care for older adults.

Participants felt that a specific coordinator role could be valuable however this role would not be of benefit to patients and providers unless it was supported by better engagement of patients and families in decision-making, as well continuity of care across the health system. Literature suggests that caring for and supporting patients and families includes utilizing the right services, at the right time, determined by level of complexity (Rothman & Wagner, 2010).

The fourth and fifth themes, *lack of standardized referral processes and follow-up, and identifying services in the community for older adults*, touched on current processes that occur when trying to organize services for older adults. Data provided evidence that suggests multiple communication methods are used to make referrals. Furthermore, providers acknowledged they are unfamiliar with all of the services available in the community, and sometimes referrals to services are not made on behalf of the patients when they should be. These are areas for significant improvement to primary care for older adults. Literature demonstrates the need for multidisciplinary care for older frail adults because it significantly reduces fall risk, hospital use and nursing home admissions (Beswick et al., 2008).

The final theme that was developed from the interview data, *caring for older adults in rural communities*, identified some of the unique challenges and facilitators when providing care for older adults in rural communities including, community care providers working across large geographical regions, “everybody knowing everyone”, and the importance of building trusting relationships. Although there were some strengths of rural communities identified, such as providers knowing who to contact for services, there are significant challenges. There are not enough health care providers to adequately serve the number of older adults in rural communities (Keating & Eales, 2012). Rural communities are described as wealthy in terms of social networks that can support older adults, however there is a lack of available community

resources to support older adults who wish to age in their own home (Keating & Eales, 2012; Sims-Gould & Martin-Mathews, 2008). The lack of access to specialists also poses a significant challenge for individuals who need geriatric support for complex health conditions.

This project also included an analysis of the CIHI Provider Survey that provides information on team functioning and satisfaction. For the most part, both primary care teams report that they are functioning well, providers feel that people on their team knew their own roles and those of others. Responses to the survey identified system issues consistent with the qualitative data, including issues experienced in getting information in a timely manner (including being aware of a patient receiving care from other providers or having an emergency department visit), and issues in coordinating patient care with providers from across the system.

4.4.2 Future Directions

The Chronic Care Model

The Chronic Care Model (CCM) is a well-established framework for guiding care improvements in the health care system. This phase of the project resulted in the identification of many issues experienced by providers when providing care to older adults in primary care settings. These issues were mapped onto the Chronic Care Model (CCM) in Figure 4.1, below. This illustrates areas that should be addressed in health system improvement initiatives. This indicates the areas of the system that future work should focus on to improve chronic illness care. Specifically, there is no standardized process for identifying at-risk individuals or process for referring individuals to services. As indicated in the interviews, current assessments used in

primary care focus on specific chronic diseases, such as diabetes or hypertension. O’Caoimh and colleagues (2015) suggests that a risk screening tool focusing on caregiver support; self-reported health, or activities of daily living would be appropriate for community-dwelling older adults. Literature emphasizes the need to screen older adults who are at risk and plan care accordingly (McCarthy et al., 2015; Wodchis et al., 2016). Specifically, McCarthy and colleagues (2015) reviewed care models designed to improve outcomes and reduce health care costs for complex patients. This review indicated several common attributes of successful care models including, targeting individuals most likely to benefit from services; the need for comprehensive assessments; care planning; engagement of patients in self-care and the need for coordinating referrals to community resources.

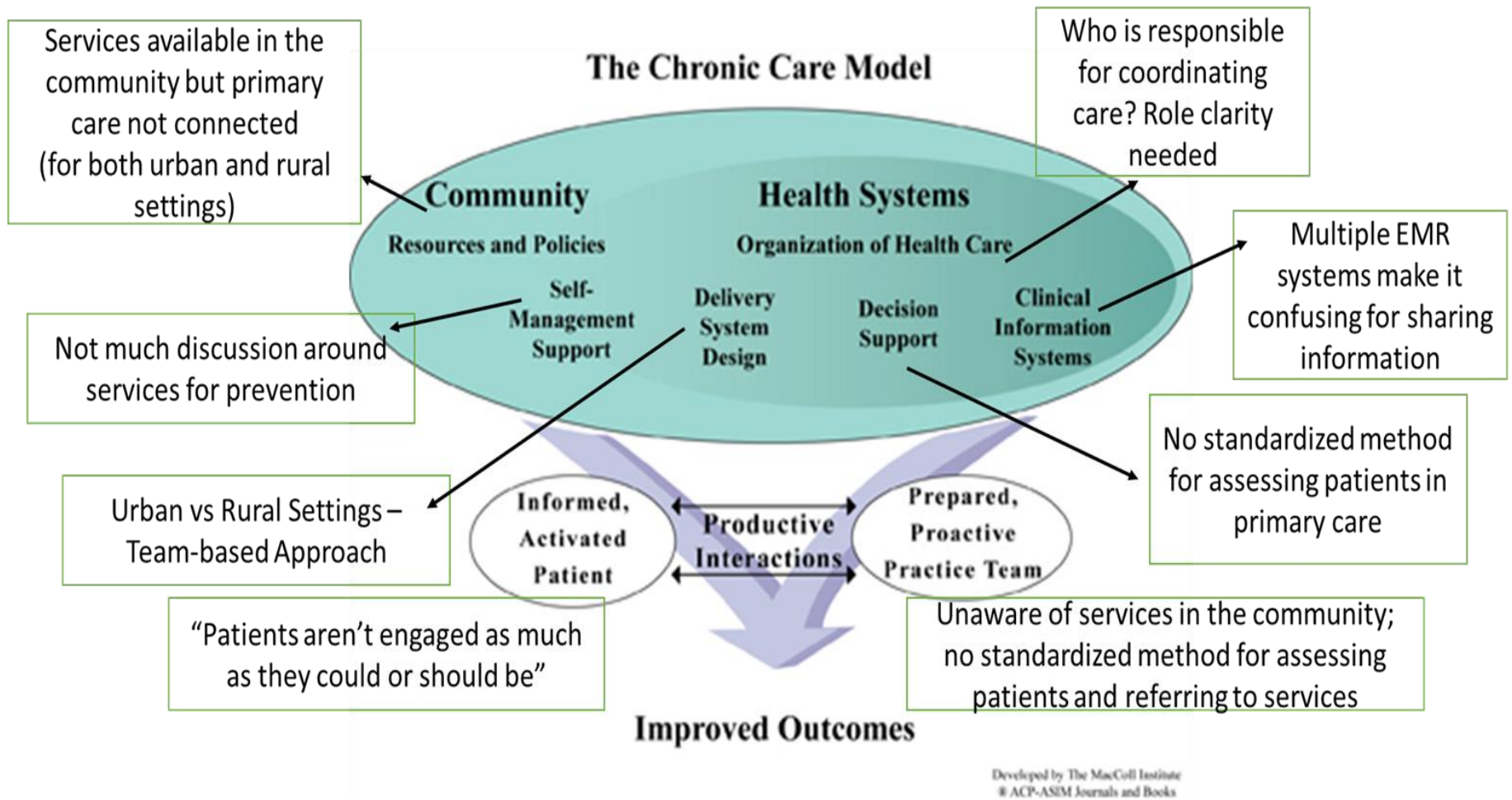


Figure 4.1. Primary Care Issues & the Chronic Care Model

This study resulted in more detailed understanding of the primary care environment as it relates to providing care to older adults. This project identified specific issues related to caring for older adults including lack of involvement of older adults in care planning; trouble coordinating care across the system, including challenges with sharing and receiving information; and limited knowledge by primary care providers of appropriate services for individuals in the community. Based on the findings of this research, further education is necessary for both providers and patients in terms of service availability as well as the importance of engagement in decision-making and how this can be achieved. This research also identified the need for a database that houses all of the community service options and a standardized method for coordinating care for older adults.

Based on these results, subsequent chapters will focus on developing and implementing improved processes for coordinating care in primary care, using risk screening and referral mechanisms.

4.4.3 Limitations

A limitation of this study is the recruitment process. The researcher used networks in the community to make connections with community care providers who might be interested in participating, limiting access to the smaller organizations who may not be as well known in the community. Secondly, the study is limited to only two sites within one Canadian province and therefore the results may not be representative of other primary care teams across Ontario or Canada. However, a rural and urban location were selected to illustrate two different contexts. Another limitation of this study is associated with the provider survey that was distributed to providers in both primary care locations. There were a limited number of non-nurse health care providers who completed the provider survey. Survey results represent the views of those who

completed the survey, rather than the entire primary care team. Due to anonymity of responses on the provider survey and different sampling methods, it is not possible to directly link specific qualitative responses with specific quantitative survey results. Lastly, there was limited opportunity for on-site observations. During this phase of the study, patients and caregivers had not been approached about the study and therefore provider-patient interactions to observe actual processes of engagement or care coordination could not be completed.

4.4.4 Conclusions

Overall, this study has provided useful information that will be used in the next phase of the research project. Improvements can thus be made to advance care for older adults that are informed by an in-depth understanding of the current operations and context of primary care teams.

5.0 USING DEVELOPMENTAL EVALUATION TO IMPROVE CARE COORDINATION FOR OLDER PATIENTS IN PRIMARY CARE

Abstracts

BACKGROUND

The health care system is complex, with multiple interacting components, and this complexity needs to be taken into account in implementing and evaluating health care programs. Innovation in complex systems may need to be developed iteratively, with ongoing feedback and evaluation, to identify the elements of needed improvements and appropriate methods for their implementation. The aim of this study was to develop and implement improved care coordination for older primary care patients, using an approach consistent with complex systems.

METHODS

A developmental evaluation approach was used to develop and implement improved care coordination using a screening and referral process for older patients in two primary care settings (one urban, one rural), over a period of six months. The Implementation Framework of Chaudoir and colleagues (2013) was used to guide implementation. Elements of an improved care coordination process were identified collaboratively and iteratively; informal feedback was gathered throughout to inform modifications. For this project we involved system level decision-makers to align this effort with regional health system priorities. A project advisory team (n=6) was created to assist with the development of the care coordination process.

RESULTS

Consultation with primary care team members and representatives of community services identified efficient methods of risk screening and referral as needed elements of improved care coordination processes. Using information from consultations with health care providers, literature and prior research, the Assessment Urgency Algorithm (AUA) was selected as an appropriate risk-screening tool for use in primary care. An online referral tool, Caredove, was selected to support direct referrals during the care coordination process. Modifications were made through informal feedback including, (i) making the screening tool electronic; (ii) creating an information pamphlet for patients; and (iii) considering roles of primary care team members who could support implementation.

DISCUSSION

This study resulted in the identification of needed elements of improved care coordination for older primary care patients, and specific methods for their implementation. Lessons relevant for future implementation of innovations in primary care include: the importance of staff buy-in, the inclusion of a patient representative on the advisory team, and the importance of ongoing communication with the primary care team. Developmental evaluation proved to be an appropriate approach for developing and implementing programs for complex health care settings.

5.1 Background

5.1.1 Complex Health Systems

Health care systems have become increasingly complex and consequently, there is growing recognition of the relevance of complexity theory to understand health system functioning, and to guide health care research and evaluation (Plsek et al., 2001; Counsell et al., 2007; Guzman et al., 2008).

Systems may be identified as simple, complicated or complex. Systems which are simple have both a high degree of certainty and high degree of agreement about what might emerge in a given environment. In a complicated systems, there may be either a lower degree of certainty or a lower degree of agreement (Patton, 2011). However, complex systems have neither high levels of certainty nor high levels of agreement and evaluation of complex systems has proven to be challenging, largely due to the many unknown factors at play and the difficulty in predicting and identifying relevant outcomes at the beginning of the evaluation (Patton, 2011).

5.1.2 Complexity Science

Health care organizations can be viewed through a lens of complexity science (McDaniel & Driebe, 2001; Tan et al., 2005). Complexity science is the study of systems that are characterized by nonlinear (improbable, unpredictable and unexpected) dynamics and emergent (interacting and self-organizing) properties (McDaniel & Driebe, 2011). Uncertainty (uncontrollable, unknowable); adaptive (agents responding to each other and new environments); dynamical (interactions between, within, and among all subsets in a system); and co-evolutionary (agents evolve with the system overtime) are also characteristics of complex systems (Patton, 2011).

Complex adaptive systems (CAS) are comprised of a large number of interacting parts making their structure and behaviour difficult to understand and predict (Tan et al., 2005). Health care can be classified in complexity science as a complex adaptive system (CAS) (McDaniel & Driebe, 2001) comprised of multiple interacting services, participants and stakeholders (Tan et al., 2005). Study of CAS requires a shift from single process thinking towards thinking in patterns, interrelated processes and relationships (Stroebe et al., 2005). Geriatric health services have nonlinear and dynamical characteristics due to the uncertainty, unpredictability and uncontrollable events that could take place following an admission into the health system (Tan et al., 2005). For example, when older adults experience a serious illness or health event such as a hip fracture, they may see a number of health care providers (e.g., nurse, surgeon, physiotherapist, homecare nurse), undergo multiple different assessments, and transition through a number of different care settings during their therapy and rehabilitation, all generating uncertainties and complexities (Tan et al., 2005).

Older Adults in a Complex System

Frail, older patients, and the health systems which care for them, may be particularly complex. The proportion of adults over the age of 65 has increased to nearly five million over the past few years in Canada, and it is anticipated that this number will continue to increase exponentially (Statistics Canada, 2012). Many older patients are considered 'complex' as they may experience multiple chronic conditions and functional disabilities that require a variety of health care services with unpredictable outcomes (Findlay et al., 2010). The current health care system is ill-equipped to deal with the needs of complex older adults as their care is often provided in silos, making it difficult to coordinate and navigate care across the continuum

(Béland et al., 2006), resulting in older adults either not receiving timely and effective care or becoming lost in the complex system all together.

Purpose: Using the information gathered in phase one of the study, along with prior research and literature reviews, it is evident that improved care coordination for older adults in primary care is needed. The aim of this paper was to develop and implement an improved process of care coordination for older primary care patients, using an approach that takes into consideration complex systems. Specifically, this paper aims to answer, *what are the factors influencing the implementation of improved care coordination, including organizational and environmental barriers and facilitators?* Evaluation of the resulting process is described in the next chapter (Chapter 7).

5.2 Methods

5.2.1 Developmental Evaluation Process

Due to the multiple interacting components of a complex system, it is difficult to use traditional research tools to study the impact of changes from healthcare interventions. A developmental evaluation approach has been proposed for situations where complexity makes it difficult to identify and design the necessary elements of an intervention at the outset, and these need to be identified and tested through an iterative and adaptive process (Patton, 1994) Patton defines developmental evaluation as *“processes and activities that support program/organizational development. The evaluator becomes part of the team to conceptualize, design, and test new approaches in a long-term, on-going process of continuous improvement, adaptation, and intentional change”* (Patton, 1994, pg.317). This approach is consistent with the Medical Research Council (MRC) guidelines for developing and evaluating complex

interventions, which suggests that developmental work should take place prior to formal program evaluation (Craig et al., 2008). In this project, the development and refinement of the process of care coordination is thus guided by active, ongoing engagement with the primary care team, patients and family members.

For this project, a developmental evaluation approach was chosen as a method appropriate for developing and evaluating change interventions in complex systems, such as health care. Developmental evaluation, is similar to participatory action research (PAR; Baum et al., 2006) in that it involves working with persons directly involved in a program to make program changes. Similarly to PAR, developmental evaluation involves an iterative process of collecting information and making changes and involves the researcher working in partnership with the participants (Baum et al., 2006; Patton, 2011). However, developmental evaluation supports innovation within an organization of high complexity (such as the health care system). Developmental evaluation works particularly well in situations of unpredictability and where partnerships could last for long periods of time (Patton, 2011; Gamble, 2008).

The program changes and interventions developed in this phase will be evaluated, using an ethnographic approach, in the next phase of the project, with the goal of achieving a scalable system of coordinated care for older adults in primary care.

5.2.2 Implementation Framework

A multi-level framework will be used to help guide the implementation work. Building on the work of Damschroder and colleagues (2009) in implementation of health services research (Consolidated Framework for Implementation Research (CFIR), Chaudoir and colleagues recognized the need to include a patient-level factor (Chaudoir et al., 2013). Figure

5.1 depicts the resulting framework, which includes five categories to consider when implementing health innovations: environmental factors, organizational factors, patient factors, provider factors, and program-related factors.

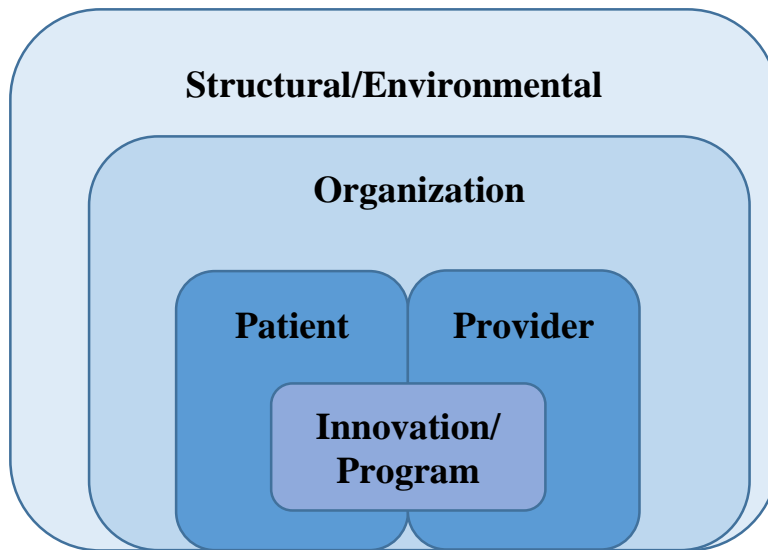


Figure 5.1. Multi-Level Implementation Framework

Structural/environmental factors include the larger context in which the organization is situated, including the physical environment, public policies or infrastructure. Organizational-level factors refer to aspects of the organization including type of leadership or culture. The provider level refers to any individual provider who has contact with the patient through the implementation of the innovation; this can include physicians, nurses, or other allied health professionals. Provider-level factors include provider attitudes towards the innovation. The patient-level factors refer to the characteristics of the patients that can influence the health innovation (program) such as level participation in the program or attitudes. Lastly, the innovation (program) level factors represent what is being implemented. Table 5.1 below outlines the framework component and the associated method that was used to obtain information related to that component.

Table 5.1. Implementation Framework and Associated Methods

COMPONENT	EXAMPLE	METHOD USED TO OBTAIN INFORMATION
SYSTEM	Public Policy/Infrastructure	Focus group with providers (phase one); project advisory group with system level representatives
ORGANIZATION	Funding Model; Management Style	Site meetings; informal feedback from manager; observation of workflow
PROGRAM	Innovation being implemented	Developmental evaluation process to obtain feedback on the implementation of screening and referral mechanisms
PROVIDER	Attitudes towards program	Informal feedback and meetings with health care providers
PATIENT	Characteristics that may influence program	Process was reviewed by Seniors Helping as Research Partners (SHARP) group

Specific attention to these five categories will be made during the data analysis phase to assist in identifying key factors influencing implementation of care coordination in the study sites;

these learnings could then guide implementation in other primary care settings.

5.2.3 Consultations, Feedback and Modifications

Discussions were held with health care providers and system-level decision-makers to discuss the process of implementing a process that would allow for better care coordination for older adults. System level decision-makers were consulted in order to align these efforts with regional health system priorities. The researcher along with these decision-makers formed a project advisory team (n=6) that oversaw the rollout of this project in two study sites. Multiple hour-long telephone conversations between the months of January – March 2015 to discuss the implementation process at the study sites.

Study site participants had the opportunity to provide informal feedback throughout the implementation process through email and phone conversations. The researcher was immersed into each study site for a long period of time to gather information and feedback about the implementation of the tools. Over a period of eight months the researcher frequently (every 1-2 weeks) attended the clinics to pick up screening forms, have conversations with providers and the manager and understand what was working and what was not working. Using this information, changes were made, aligning with the developmental evaluation process.

Developmental evaluation is an iterative process of identifying strategies and obtaining feedback to assess their appropriateness and impact. Due to the iterative nature of this process, methods may emerge and throughout the project; these are described in the results section.

Patient feedback was obtained through a focus group interview conducted with SHARP (Seniors Helping as Research Partners) members. In 2013, the *Geriatric Health Systems (GHS) Research group* launched SHARP, which is a group that includes more than 60 older adults

from the Waterloo Wellington community (www.uwaterloo.ca/ghs/SHARP). This network is made up of individuals with diverse backgrounds, experiences, and health statuses; these members participate as partners in multiple research projects. A focus group interview (n=8) was conducted to gain a consumer perspective on implementing a screening and referral process into primary care.

5.3 Results

5.3.1 Consultations

The information from Phase 1 focus groups and interviews with health care providers, provided necessary background information to start conversations about the need for better processes in primary care for coordinating care for older adults. Participants in phase one identified the need for a database with community services and a method for identifying which patients would benefit from service referrals. Meetings were held with the project advisory team to discuss the process for implementing a screening tool and referral mechanism into primary care. Figure 5,2 below outlines the process that was followed including the phase 1 consultations (described in Chapter 4), the development of the referral pathways and the team training (described in this chapter) and the larger evaluation (described in Chapter 6).

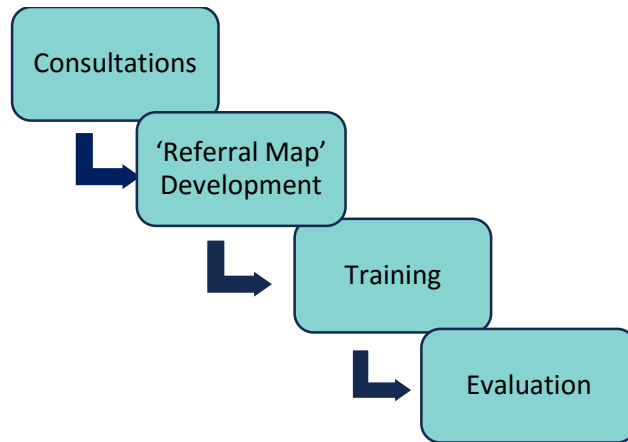


Figure 5.2. Implementation Process

First and foremost, decisions about the specific screening and referral method needed to be made. The information provided below, outlines the results of these discussions.

Screening Tool Decisions

The information gathered from initial focus group interviews indicated that some process was needed to refer patients to services sooner,

We are getting people way too late, if they had called us much sooner we could have been a lot more helpful and supportive to the client and to their families but they wait and then it's late – Community Care Provider (Urban)

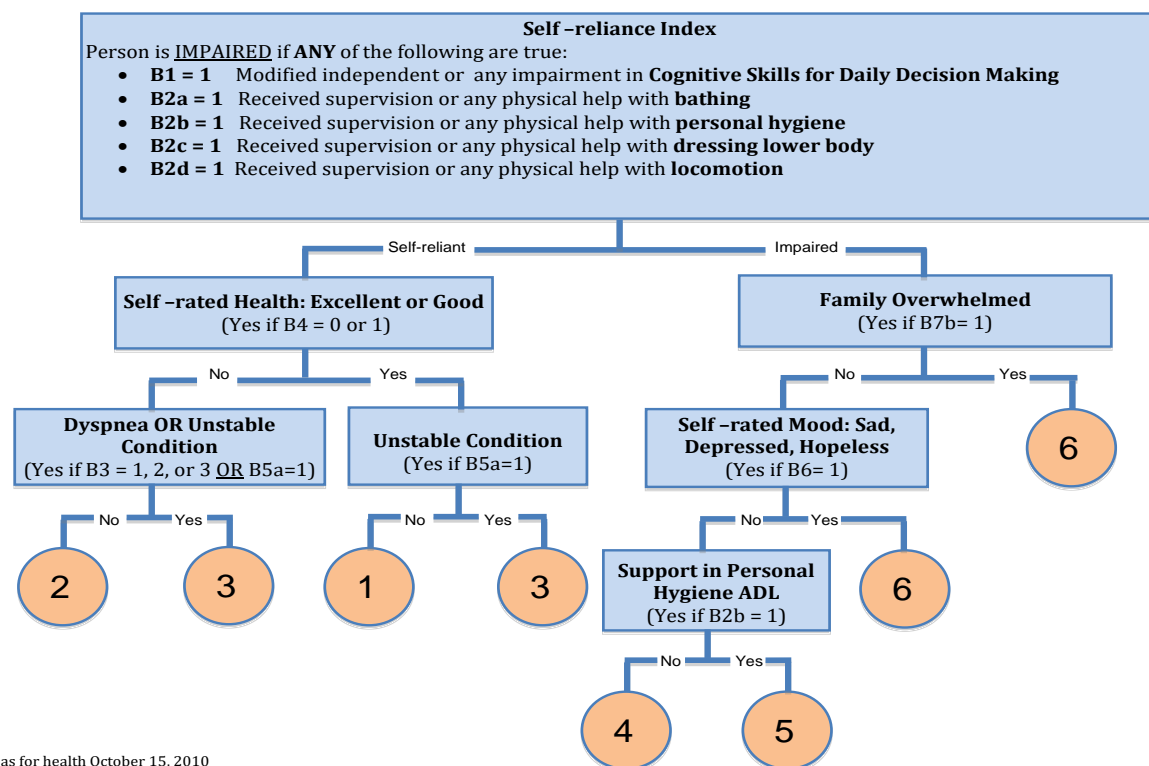
I'm excited about this [project] because you see so much caregiver stress...and you know, being able to provide these links for them to those supports are priceless. So I think that's going to make a big difference for people and their mental health and coping levels, and just keeping seniors safe for longer, and more independent – Primary Care Provider (Urban)

Consultations, literature, and provincial health system priorities pointed to the use of the interRAI Assessment Urgency Algorithm (AUA; Hirdes et al., 2010). The AUA approach is consistent with the recommendations of O’Caoimh and colleagues (2015) that a short instrument covering age, activities of daily living, caregiver availability, self-reported health and recent health care utilization is necessary for risk-prediction of older community-dwelling individuals.

Primary care providers highlighted the importance of having screening tools that were brief, given the fast-paced environment. The AUA is a brief (usually < 1 minute) decision-tree algorithm that can predict levels of need (service needs) based on classifying patient risk levels as low, medium, or high. Low-risk patients (scores of 1-2) may benefit from supports for self-management and prevention; medium-risk patients (scores of 3-4) may benefit from more detailed assessment, and referrals to community services; and high-risk patients (scores of 5-6) may benefit from a more comprehensive assessment and specialist referral. The AUA may also be referred to as the Preliminary Screener (used at initial intake by Community Care Access Centres in Ontario) or the ED Screener (used in some emergency departments across Canada). For the purposes of this thesis, the tool will be referred to as the AUA and the paper version of the tool will be used (there is an app supported by Apple and Android devices available for use in the ED). The AUA paper version includes 13 questions (seven main questions with sub-questions).

To date, many of the interRAI tools have been adopted across national and international care settings, but their use in primary care is limited. In this particular region in Southern Ontario, interRAI tools are used in most health care sectors including, community care, long-term care, mental health and home care.

The primary health care team managers felt that registered nurses and medical office assistants were in the best position within the team to complete the screening. The screening was to be completed when the patient was taken into the examination room to take their blood pressure and discuss the reason for their appointment. Figure 5.3 displays the decision-tree that determines level of risk (for interpretation of variable names, e.g., “B4”, see Figure 5.7, below).



ideas for health October 15, 2010

Figure 5.3 Assessment Urgency Algorithm

Referral Map Development

During the first phase of the project, primary care participants were also asked to identify services or organizations in the community that they were familiar with, or to which

they commonly referred patients. A sample of community care providers were asked to discuss their organization in terms of services offered for older adults. This information was compiled into the Table 5.2 below by “Type of Service”, including services offered at the primary care site, community services, specialized services and informal supports.

Table 5.2. Services from Focus Group and Individual Interviews

Type of Service	Organization/Services Offered
‘In-House’ Clinics at Family Health Teams	<ul style="list-style-type: none"> - Education sessions (Nutrition, Exercise) - Outreach Teams - Occupational Therapy - Diabetes Self-Management Clinics
Community Services	<ul style="list-style-type: none"> - Alzheimer’s Society - Arthritis Society - Hearing Society - Community Behavioural Support Team - Intensive Geriatric Service Workers (IGSWs) - CCAC referral - Community Support Services <ul style="list-style-type: none"> o Transportation o Meals on Wheels o Friendly visiting o Telephone support o Adult day programs o Home care (transfers, toileting, bathing) o Support with personal care for short term o SMART exercise program – both in home and in community offered - Other Services <ul style="list-style-type: none"> o Adult Day Programs o Walking Groups o Dining Programs o Recreation Programs o Community Centres o Support Groups
Informal Supports	<ul style="list-style-type: none"> - Library Clubs - Seniors Clubs - Church Clubs

Specialized Geriatric Services	<ul style="list-style-type: none"> - Geriatric Psychiatry - Geriatrician - Geriatric Assessment Unit at local hospital - Geriatric Complex Program (at hospital)
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Using the information from Table 5.2 and evidence from prior research (CCAC data), services were organized based levels of risk, using the Assessment Urgency Algorithm. Prior research has indicated that older adults who are low risk typically benefit from informal, self-management type services such as education (Eckel, 2015). For those individuals who are moderate risk, further assessment and referral to community services may be beneficial, and for those individuals at higher levels of risk, more comprehensive assessment is necessary and patients may benefit from a referral to specialized geriatric services. In consultation with the primary and community care teams, services were organized by level of risk, as illustrated in Figure 5.4.

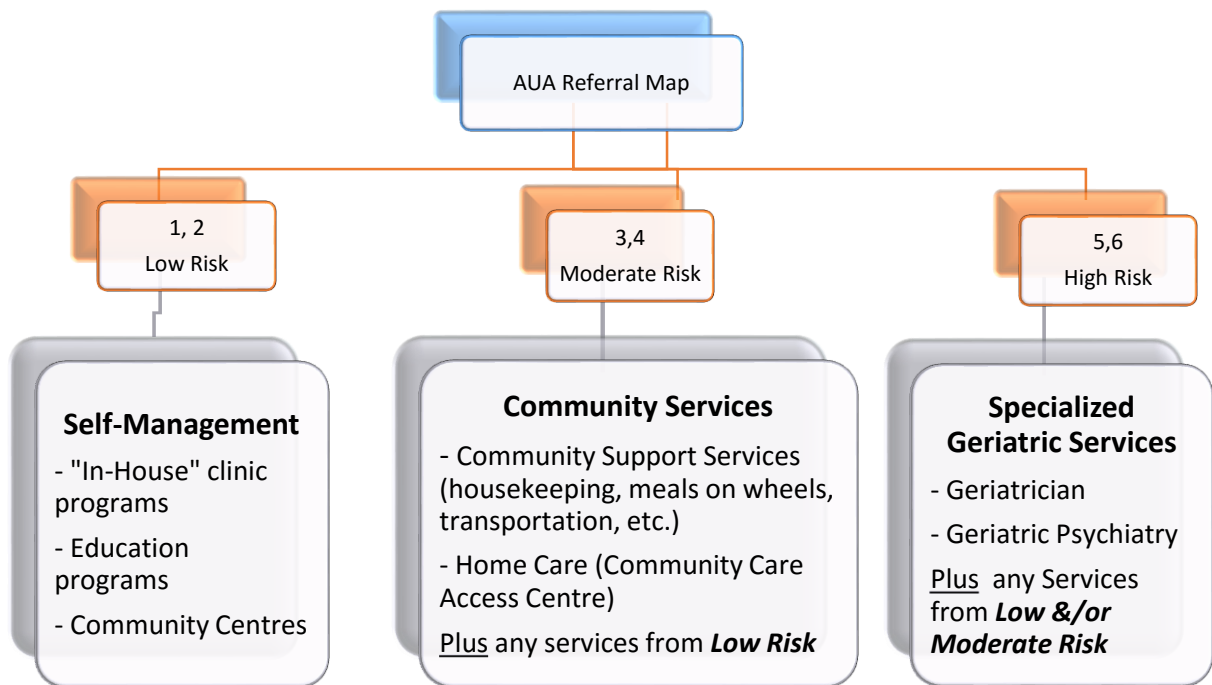


Figure 5.4. Services by Level of Risk

It was evident through the consultations and subsequent referral mapping exercise that there were a number of services in the community that would benefit older adults at each risk level. However, providers from the primary care sites were not necessarily aware of all of these services, as indicated in the quote,

I don't think that even our system partners fully understand all of the possibilities that are available to clients that ask a patient or a client what they want. You have to first educate them on what's available, if that's even like possible, and then I think that you can have a conversation about, you know, sending someone to a memory clinic versus the geriatrician or psycho-geriatrician or versus having an outreach team come to their house versus going to the clinic –
Community Care Provider (Urban)

It became apparent that a database was needed to assist providers with the referral process. In Ontario, an online program, HealthLine.ca, has been created for each region of the province and provides a list of services and organizations and their contact information. In the southern region of Ontario, an online referral platform, Caredove, has been created to support referrals across the health care system. Meetings were arranged with representatives from each online program to discuss the positives and negatives of each system. Table 5.3 provides a detailed description of the findings.

Table 5.3. Descriptions of HealthLine.ca and Caredove

	HEATHLINE.CA	CAREDOVE
Background	<p>Online directory of health and community services</p> <ul style="list-style-type: none"> - Websites maintained by CCAC -3300 organizations represented -Launched 2 years ago -Clear and steady curve within the province of increased usage - No login credentials <p><i>Pros: Public usage is high, no login required</i></p> <p><i>Cons: Not well known by some sectors in our region</i></p>	<p>Online directory of health and community support services with direct referral booking potential</p> <ul style="list-style-type: none"> -75 organizations in WW use Caredove -Populated by originators, WW networks and councils <p><i>Pros: Caredove is looking at integrating with EMRs</i></p> <p><i>Cons: not accessed by Public; requires email address; not as well populated</i></p>
Training	<p>Dedicated professional available</p> <ul style="list-style-type: none"> -takes 15-30 min 	<p>Dedicated professional available</p> <ul style="list-style-type: none"> -takes 15-30 min
Fees	<p>No Fee for usage</p> <ul style="list-style-type: none"> -Cost associated with adding record -Annual fee to organizations however it is currently covered by an organization 	<p>No fees for usage</p> <ul style="list-style-type: none"> -Current fees exist for adding organizations
Updating	<p>Updated once per year by Healthline</p>	<p>Individual organizations update care listings on their own with a dedicated professional moderating the changes</p>

Referral Capabilities	Not able to directly refer from website	Direct referral capabilities
Options	<p>1. Microsite on Healthline – web presence without maintaining a webpage</p> <p>2. Mini site – more expensive because sits outside healthline – more independent look</p> <p>Current mini-sites include: wound care, stroke network. There is a time commitment for Healthline to keep the mini-site updated which will require a fee</p>	Option to create AUA site within Caredove to organize services by level of risk

A decision was made by the project advisory committee to use the Caredove referral platform due to the direct referral capabilities. Although the site was not currently widely used in primary care, the program was able to support referrals as a result of the AUA screener result. Figure 5.5 below provide an image of the screen when a provider is searching for a service.

Figure 5.5. Caredove Referral Platform (Adult Day Program example)

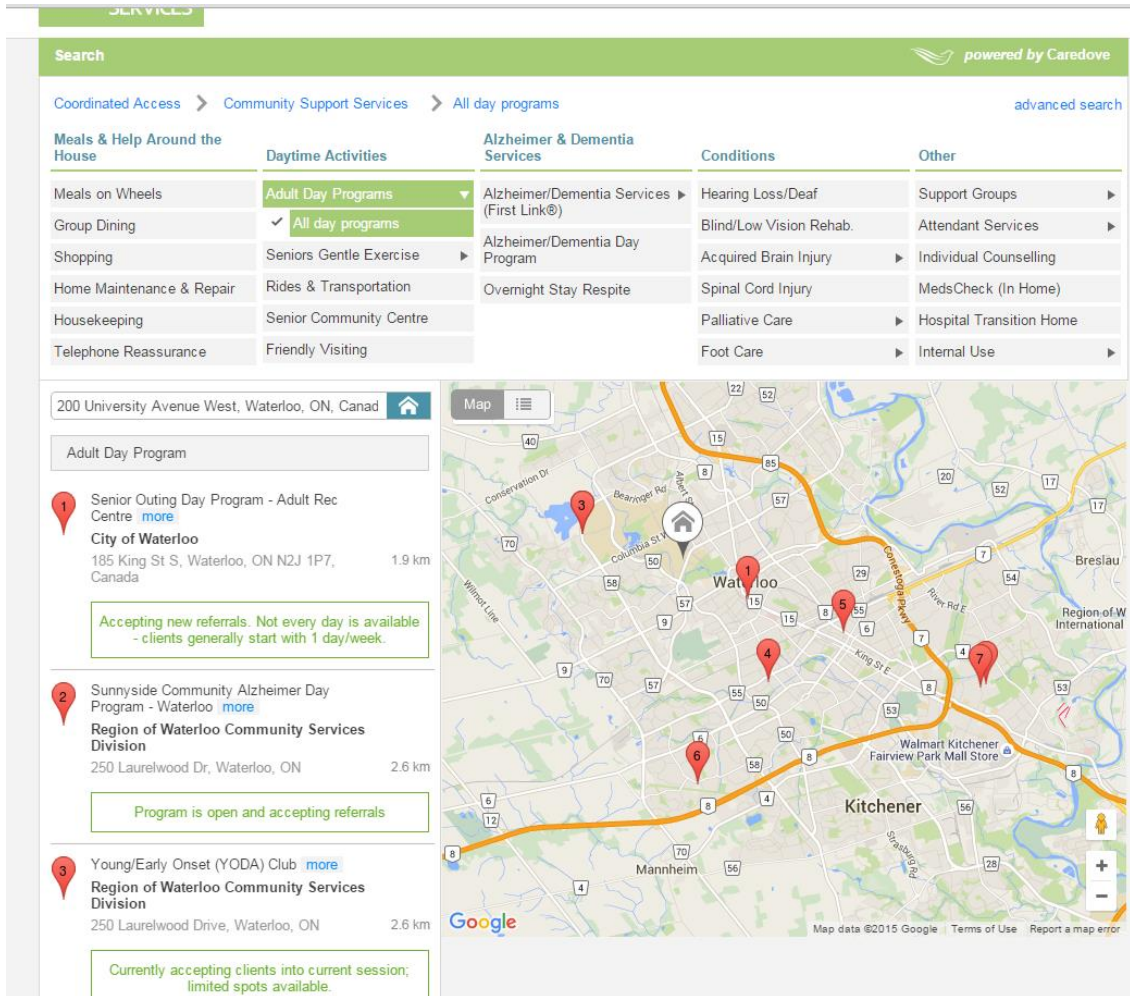
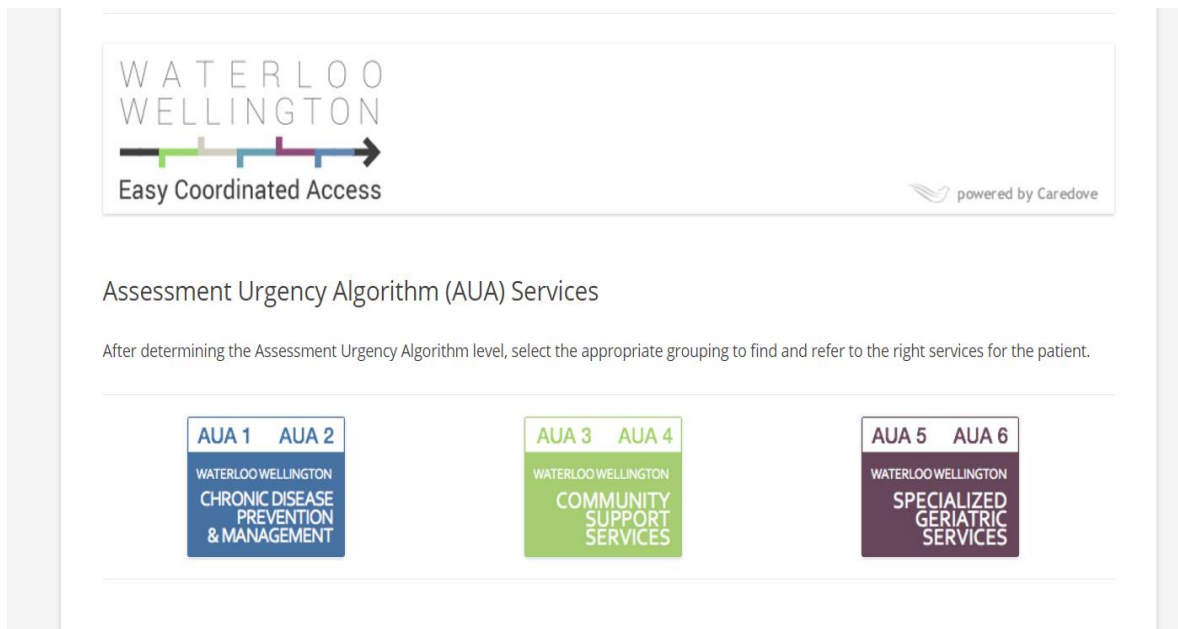


Figure 5.6 provides an image of a newly developed screen within Caredove. The project advisory team worked with the creators of Caredove to develop an interface that would link the provider to services based on the AUA score. For instance, if the patient scored an AUA 4, the provider could click on the centre button in the image below and be linked with community services such as meals on wheels, transportation, adult day programs and much more. These types of services would be appropriate and beneficial for someone who scored an AUA 4.

Figure 5.6. AUA within Caredove Website



Feedback from Older Adults (SHARP Members)

Information that emerged from the interview with SHARP members indicated general support for the screening and referral process. When participants viewed the AUA and Caredove they said,

This is very interesting. It is nice to see this could be in my doctor's office.

However, some participants had concerns about health care providers' willingness to participate in the process,

Well my only issue is that the doctors often, they don't want to be educated and they don't want to take part. So that's my concern

Most doctors aren't interested in high maintenance patients...it's tougher work and more time consuming

Overall there was support for the implementation, and the SHARP members were interested in the results of the evaluation which will be reported back.

5.3.2 Training

Primary care providers at each study site participated in a training session focused on the screening tool and referral platform. The training session lasted 2 hours in length. The training consisted of presentations and case study exercises that were completed by each participant. An interRAI educator provided the 1.5 hour training that included a presentation about interRAI as an organization and the development of the screening tool. A representative from Caredove provided a 30 minute presentation that showed providers how to log into the site, search for services and complete a referral. Training session participants were identified by the executive director as providers who would be using the AUA in daily practice. The training session at the rural study site involved 6 participants, registered nurses, registered practical nurse and an occupational therapist. The training session at the urban study site included registered nurses and medical office assistants.

5.3.3 Informal Feedback

Following the training sessions, the study sites immediately started using the AUA screening tool and the Caredove referral platform. Primary care providers were given an email address where they could send questions and give feedback at any time. It was immediately evident that using a paper version of the screening tool was not feasible; it would need to be embedded into the EMR system. Figure 5.7 shows the paper version of the screening tool.

Feedback from the nurses also indicated that the paper version required time to figure out the score and handwrite the reasons for referrals. The researcher worked with a data analyst at one of the study sites and a customizable form was created and built into the EMR. Figure X shows a screen shot of the EMR page that notifies the nurses to complete the AUA. This yellow bar shows up on patient charts for individuals 70 and older.

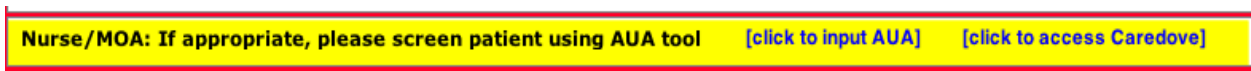


Figure 5.8. Electronic Medical Record AUA/Caredove Toolbar

Figure 5.9 provides a picture of the electronic AUA form that calculates the score automatically. It also gathers patient information (sex and date of birth) from the patient chart. The health care providers also have a space to type in information about the patient and reasons for any further recommended action.

InterRAI Preliminary Screener For Primary Care and Community Care Settings
Canadian Version v.5

SECTION A. IDENTIFICATION INFORMATION

SEX F
 BIRTHDATE (yyyy/mm/dd) 1944/01/06
 ASSESSMENT REFERENCE DATE (yyyy/mm/dd) 2015/07/21

Our team is part of a study that is looking at a particular assessment tool for seniors. The questions I will ask relate to your current health. The results will help us decide together if you would benefit from any additional information or referrals to health and community services that are provided at our team and out in the community. I will track your answers but your information will be kept anonymous with the study researchers. They will be collecting data on how we came up with the referrals most suitable for you and whether the tool was useful in supporting your healthcare. Would you let me try this tool with you? It should not take more than a few minutes of your time.

SECTION B. SCREENER

1. COGNITIVE SKILLS FOR DAILY DECISION MAKING

Making decisions regarding tasks of daily life - e.g., when to get up or have meals, which clothes to wear or activities to do

0. Independent
 1. Modified independent or any impairment

2. ACTIVITIES OF DAILY LIVING

Most dependent episode over last 24 hours. If ADL did not occur in last 24 hours, code the most recent occurrence.

a. Bathing - How takes full body bath/shower. Includes how transfers in and out of tub and shower AND how each part of the body is bathed: arms, upper and lower legs, chest, abdomen, perineal area - EXCLUDE WASHING BACK AND HAIR.

0. Independent or set-up help only
 1. Supervision or any physical assistance

b. Personal hygiene - How manages personal hygiene, including combing hair, brushing teeth, shaving, applying make-up, washing and drying face and hands - EXCLUDE BATHS AND SHOWERS.

0. Independent or set-up help only
 1. Supervision or any physical assistance

c. Dressing lower body - How dresses and undresses (street clothes, underwear) from the waist down, including prostheses, orthotics, belts, pants, skirts, shoes, fasteners, etc.

0. Independent or set-up help only
 1. Supervision or any physical assistance

d. Locomotion - How moves between locations on same floor (walking or wheeling). If in wheelchair, self-sufficiency once in chair.

0. Independent or set-up help only
 1. Supervision or any physical assistance

3. DYSPNEA (SHORTNESS OF BREATH)

0. Absence of symptom
 1. Absent at rest, but present when performed moderate activities
 2. Absent at rest, but present when performed normal day-to-day activities
 3. Present at rest

4. SELF-REPORTED HEALTH

Ask, "In general, how would you rate your health?"

0. Excellent 3. Poor
 1. Good 8. Could not (would not) respond
 2. Fair

5. INSTABILITY OF CONDITIONS

a. Conditions/diseases make cognitive, ADL, mood, or behaviour patterns instable (fluctuating, precarious, or deteriorating)

0. No
 1. Yes

b. Experiencing an acute episode, or flare-up of a recurrent or chronic problem

0. No
 1. Yes

6. SELF-REPORTED MOOD

Ask, "IN LAST 3 DAYS, have you felt sad, depressed, or hopeless?"

0. No
 1. Yes
 8. Could not (would not) respond

7. INFORMAL HELPER STATUS

a. Primary informal helper expresses feelings of distress, anger, or depression

0. No
 1. Yes

b. Family or close friends report feeling overwhelmed by person's illness

0. No
 1. Yes

SECTION C. SUMMARY

1. ASSESSMENT URGENCY ALGORITHM

Click to display: 3.0

2. FURTHER ACTION OR ASSESSMENT RECOMMENDED

- A. No
 B. Education/Support
 C. Referral to Community Support Services
 D. Referral to Community Care Access Ontario
 E. Referral to Specialized Geriatric Services
 F. Other

REASON(S):

Feels things are manageable right now, husband does cooking. Interested in light housekeeping in her home, having a hard time keeping up with it.

Referrals are based on your best clinical judgement and may not follow the predetermined categories. These categories serve as prompts for further discussion only.

AUA 1&2: education, self-mgt. and chronic disease prevention programs

AUA 2&3: community support services, CCACC, in-home support services etc.

AUA 5&6: specialized geriatric services

3. SIGNATURE OF PERSON COMPLETING THE SCREENER

Signature

2015/07/21

Date (yyyy/mm/dd)

Figure 5.9 Electronic Screening Form in EMR

Other feedback provided by the health care providers completing the forms included the need for a patient handout. The providers wanted information that they could give the client about services that were discussed during the visit. It was found that sometimes patients wanted some time to think about the services they were being offered. The following quotes support the creation of an information pamphlet for the patient.

They are interested but not ready to make a decision when they're here...so I show them the options...but I need something to hand them so they remember –
Primary Care Provider (Urban)

Anything you hand a patient from your visit is only beneficial. Because they have that reference when they go home. Very, very helpful, and we're doing that with other things in our practice...at the end of their visit, when you're back for a follow up, this is what you learned today, this is what I need you to work on...
- Primary Care Provider (Urban)

The researcher worked with the providers and with a group of older adults to create a pamphlet. Three pamphlets were created, each geared towards low, moderate or high risk AUA scores. Providers felt that pamphlets should not identify risk level for fear that it could upset the patients, and the researcher was told to avoid the colour red. Instead, low risk aligns with light teal and high risk aligns with dark teal. The group of older adults suggested that the name of the referring provider should be listed so that patients know who to contact if they have questions after the appointment.

The pamphlets were designed with input from members of the SHARP group and put through readability software to ensure they were suitable. Figure 5.10 provides an illustration of the three pamphlets, front and back.

Lastly, health care providers who are currently using the screening the tool suggested that other team members should also learn about and use the tool. One provider suggested nurse practitioners,

I would really think the nurse practitioners should be part of the program, because I think they would have a lot more time, not a lot more time but they have a little bit more time than we do to see each patient, because I think they get a 15 minute spot, whereas we only have 10 and that includes the time with the doctor. – Primary Care Provider (Urban)

A meeting was conducted with the nurse practitioners at the clinic –

During the meeting, the nurse practitioners (NPs) seemed very interested in the project, they agreed that this aligned well with their work and they see a large proportion of the senior population at the clinic. They wanted to participate however they have no nursing support, so although they have 15 minutes with a patient, they also have to check blood pressure, go over lab results, discuss reasons for visit. This wouldn't leave much time. The NPs were going to speak with the manager to see if they could get nursing help before committing to the project. – Observation from meeting (September 2nd, 2015)

A follow up discussion was held with the clinic manager, however the clinic is not in a position to rearrange nursing staff at this time. The manager felt that they could revisit this suggestion soon.

5.4 Discussion

5.4.1 Summary of the Development and Implementation Process

The purpose of this chapter was to understand the process of implementing a screening tool and referral process in primary care. The development and implementation process

included consultations with a project advisory group; creation of referral pathways; training; and informal feedback and modifications. The process was documented and described in this paper.

The researcher worked with a project advisory team to gather information and make a decision about the screening and referral tools that would be tested in a primary care setting. Through consultations, literature reviews, and prior research, it was decided that the Assessment Urgency Algorithm would be an appropriate screening tool. Caredove was also chosen as an appropriate mechanism for coordinating care for older adults due to its capacity to make direct referrals.

Training sessions were held with the primary care teams to provide education on the AUA and Caredove. During the training session, providers had the opportunity to trial the tool, explore Caredove and ask questions for clarification. Informal feedback was collected from providers as they started using the AUA and making referrals on Caredove. Modifications to the care coordination process were made based on the feedback that was received.

Over the course of this process a number of lessons were learned that would be helpful in future implementation efforts in primary care clinics. First, providers prefer electronic forms over paper forms because it allows for the process to be completed more efficiently and with minimal error. Research shows that the use of standardized electronic documentation results in more complete, accurate information on patients (Miller et al., 2005). Having the assessment in an electronic format allows for easier sharing of information across the health system. For higher-risk individuals, electronic health information supports care coordination by allowing for communication between multiple providers (Hillestad et al., 2005).

Secondly, it was also evident that ‘buy-in’ to take part in a new program was needed from the entire primary care team. When assessing organizational readiness to adopt a new program or make a change, it is important to have support from the entire team including the physicians, nurses, administration staff, and clinic managers (Shaw et al., 2013).

Lastly, regularly scheduled “touch base” times were necessary to ensure that process was being followed appropriately. Frontline providers mentioned that scheduled meetings would have been helpful to continue reminding them about the project and to share case study stories with each other.

Overall, the developmental evaluation process helped to foster buy-in and support from those individuals involved. Having the support of participants allowed for feedback and collaborative discussions to help refine the process of care coordination in a primary care setting.

Aligning with the Implementation Framework

An implementation framework (Chaudoir et al., 2013) was used to support a care coordination process being put into everyday practice in primary care clinics. It is important to look at each level of the framework to further understand the influence of a new program. Structural and environmental factors include the larger context in which the organization is situated, in this case the broader health care system. Although implementation at the organizational level was positive, there are a number of issues that need to be dealt with at a larger systems level. For instance, due to multiple EMR systems used across the health care

system in the region, the completed assessment cannot be passed onto the community agency that may be assisting the patient. As a result, the community agency will repeat the assessment. A report by the Change Foundation (2010), based on interviews with a number of community care coordinators found that many felt that there was a substantial waste of resources due to repeating assessments and the lack of sharing of information among providers in different health sectors (Baranek, 2010).

Organizational-level factors refer to specific aspects of the primary care clinic. Both study sites are comprised of team-based health care providers. Prior to implementation it was important to consider how processes aligned with the current workflow of the clinic and the values of the clinic. The two primary care teams supported this work because it provided a mechanism to coordinate care for individuals who would benefit from more support, aligning with the clinics focus to provide high quality, patient-centred health care services. The developmental evaluation approach allowed for an iterative process to determine how the tools could be implemented in a way that would limit the disruption to current workflow. The provider level refers to the individuals who will be participating in new program. Provider support is necessary for successful implementation of the process. The patient-level and program-level represent the focus of this project. This information is displayed in Table 5.4 below.

Table 5.4. Results aligned with Implementation Framework Components

COMPONENT	EXAMPLE	RESULTS
SYSTEM	Public Policy/Infrastructure	<ul style="list-style-type: none"> • Multiple EMR systems cause issues with sharing information
ORGANIZATION	Funding Model; Management Style	<ul style="list-style-type: none"> • Buy-in needed from entire team; management support necessary for implementation • Implemented screening and referral process with nursing when they first brought patient into the room • Other providers felt NPs should be involved, but need larger organization change to support that • Even in a team-based approach; nurses found it difficult to have conversations with patients ensuing from the AUA due to time limitations
PROGRAM	Innovation being implemented	<ul style="list-style-type: none"> • Developmental evaluation was used to obtain feedback on the implementation of AUA and Caredove – changes were made including moving from paper form to EMR-based screening tool
PROVIDER	Attitudes towards program	<ul style="list-style-type: none"> • Informal feedback and meetings with health care providers
PATIENT	Characteristics that may influence program	<ul style="list-style-type: none"> • Risk screening tool chosen that identifies patients with varying levels of risk • Initially the process was reviewed by Seniors Helping as Research Partners (SHARP) group; however there was no patient representative on the implementation team

5.4.2 Future Directions

This study followed the process of implementing an innovative process in primary care settings. Future work could consider how implementation of a program at a primary care level can influence change in other areas of the system. For instance, if community care agencies had access to the assessment that led to the referral, they may be able to coordinate care more efficiently.

Based on the findings of this research, there are number of key lessons for future implementation:

1. Having support from all primary care team members is essential.
2. A patient representative should be included as a stakeholder during the implementation process, as indicated by the implementation framework
3. Ongoing communication and regular meeting times will support positive implementation of a program.
4. Having available resources is critical to the success of the project, including implementing a program that aligns with the current workflow of the clinic.

It would be beneficial to trial the implementation process in different health care settings.

Overall, the implementation framework provided components that need to be considered when implementing a program, however the framework did not provide significant guidance for how the implementation should happen.

5.4.3 Limitations

Generalizability of these results are limited to team-based primary health care settings. The success of this project was based on the willingness of the teams to participate, the support of managers, and the resources available in a larger team practice.

The SHARP group was consulted to gather older adults' perspective at the beginning of the study process but unfortunately there were no patient representatives on the implementation team. Patient input will be addressed in the next chapter during a formal evaluation where feedback from patients and caregivers is central.

5.4.4 Conclusions

Overall, a developmental evaluation approach is a promising method for implementing programs into complex health settings. The framework by Chaudoir and colleagues (2013) can provide information on the components that should be considered during an implementation process. Feedback throughout the implementation process allowed for continuous improvements. In the end, a process of care coordination, using the AUA screening tool and the Caredove referral mechanism was executed in two primary care teams. The care coordination process will be further evaluated in the following chapter.

6.0 COORDINATING CARE FOR OLDER ADULTS IN PRIMARY CARE: RESULTS FOLLOWING THE IMPLEMENTATION OF A RISK SCREENING AND REFERRAL MECHANISM IN FAMILY HEALTH TEAMS IN ONTARIO

Abstract

BACKGROUND

Primary health care may be the best place within the health system to provide and coordinate care for at-risk older persons, but at present is poorly positioned to meet this need. Recent reviews have found that an effective care model for complex patients requires appropriate targeting, engagement of patients and caregivers in decision-making, and coordination with other health services. This phase of the dissertation project aims to understand the perceptions and experiences of providers, patients and caregivers with implementation of care coordination processes.

METHODS

This study is guided by a concurrent transformative mixed methods design, within a developmental evaluation approach, to evaluate the care coordination process. Data were collected using ethnographic observations, individual interviews with health care providers, patients and caregivers, and survey and tracking forms. Data were analyzed using qualitative and quantitative techniques. Patients, family caregivers, and health care providers were purposefully sampled from two Family Health Teams in Ontario (rural and urban) for interviews.

RESULTS

Screening for level of risk was completed for 512 patients using the interRAI Assessment Urgency Algorithm (AUA) and care was coordinated for individuals based on level of need. Among those screened, 70% of individuals screened as low risk, 25% were screened as moderate risk, and 5% were screened as high risk. Based on the identified level of risk, service referrals were made to self-management supports, community resources, and specialized geriatric services using an online referral mechanism. Although the screening and referral process is time consuming, health care providers, patients and caregivers identified many benefits including, early identification of service need, awareness of services available in the community, and improved relationships between patients and providers.

DISCUSSION

A process of risk-stratified care coordination is possible in team-based primary care settings, and offers potential benefits for older patients, caregivers and health care providers. However, taking the time to have meaningful conversations with patients was still a challenge, and organizational structures and funding models may need to be modified to support fuller implementation. Future research should focus on testing this process in other regions, and in other practice models (such as in solo-physician practices).

6.1 Background

Primary health care may be the best place within the health system to provide and coordinate care for at-risk older persons, but at present is poorly positioned to meet this need. Reviews have found that an effective care model for complex patients requires appropriate targeting of service need to address risk (through screening), engagement of patients and caregivers in decision-making, and coordination with other health services (McCarthy et al., 2015).

Consistent Screening and Assessment of Frailty in Primary Care

The World Health Organization (WHO) suggests that 70% of chronic diseases are preventable if identified early (WHO, 2005). Screening tools are often used for early identification of those who need further assessment and who can benefit from interventions (Keller et al., 2007). Frailty is also usually identified only in the late stages, which has high economic and social consequences including greater risk of hospitalizations and increased reliance on services, and which limits the potential for positive outcomes (Lacas & Rockwood, 2012; Yu et al., 2015). Identifying frailty and risk status in primary care settings can predict adverse outcomes and guide appropriate care planning for the individual (Lacas & Rockwood). Although physician appointments are often brief, a short risk-stratification instrument can effectively identify high-risk individuals (O’Caoimh et al., 2015). An effective screening approach can lead to individualized care plans that align with patient needs and risk levels, allowing for coordination of care across multiple providers and settings.

Care Coordination and System Navigation in Primary Care

Many older adults require care from multiple providers across multiple settings, but find this care is often poorly coordinated in a complex health system (McMurray et al., 2013;

Bodenheimer, 2008; McCarthy et al., 2015). This can lead to inadequate transfers of information, medication errors and other adverse events, and poor outcomes (Kripalani et al., 2007). Care coordination strategies attempt to integrate the care of a patient among multiple health care providers, across different organizations. Patients and families also need support in understanding how to access the right services, at the right time (Sinha, 2012). Goodwin and colleagues (2013) suggest that primary care is an appropriate place within the system to assume the responsibility of coordinating care by becoming the centralized referral source. Goodwin and colleagues (2013) also indicate that this is done effectively with use of risk stratification and joint care planning.

Patient and Caregiver Engagement

There is growing recognition of the importance and benefits of engaging patients and families in joint care planning (Barry & Edgman-Levitan, 2012). A more active role for patients in their health care can improve the quality, efficiency, and outcomes of care (Coulter et al., 1999; Coulter & Ellins, 2007). Davis and colleagues (2005) found that an engaged patient is more likely to understand their health conditions, to participate in proposed treatment plans, and to report greater satisfaction with their health care and with their quality of life. In primary health care settings, care providers have long-term connections with their patients allowing for better care coordination.

This phase of the dissertation project aims to understand the perceptions and experiences of providers, patients and caregivers with implementation of care coordination processes.

Specifically, this paper aims to answer the following sub-questions: i) What are the perceptions and experiences of *providers* with implementation of care coordination processes, to inform how these processes should be modified or to understand factors important for future

implementation? ii) What are the perceptions of *patients and caregivers* with implementation to see how processes might be modified and to understand what factors are important for future implementation? and iii) Does implementation of processes for improved care coordination affect providers' satisfaction with team functioning and service delivery?

6.2 Conceptual Framework

This phase of the thesis project is guided by the Chronic Care Model (CCM), an organizational framework for improving chronic care practices (Wagner, 1998). The CCM has been widely used for health system improvements, including improving care in primary care settings (Rothman & Wagner, 2003.). The Figure 6.1, below, illustrates six components, demonstrating a multifaceted framework for care improvement. The evaluation will be guided by the framework, including asking specific questions about the components of the framework (e.g. do you feel engaged/informed about your care?) and including the broader system (e.g. understanding community services and organization design).

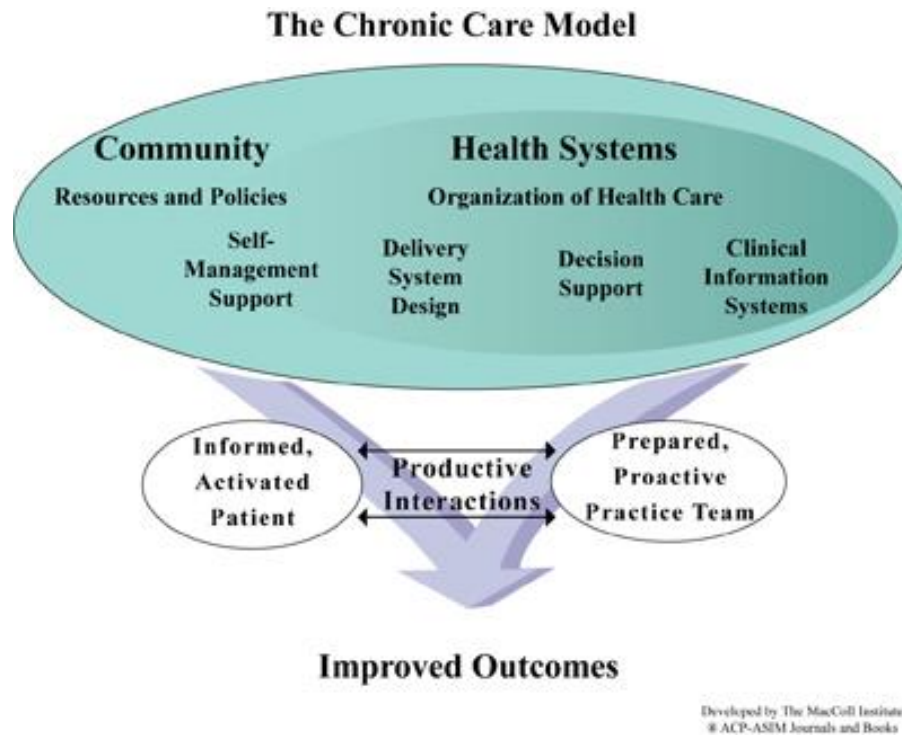


Figure 6.1. The Chronic Care Model

6.3 Methods

6.3.1 Mixed Methods

Building on the developmental evaluation approach in chapter two, this phase of the study evaluates the process of screening older adults for level of risk (using the Assessment Urgency Algorithm) and coordinating services based on that level (using Caredove as the referral mechanism). This study is guided by a concurrent transformative design within a mixed methods approach. A transformative paradigm involves ongoing data collection that encourages the use of information to make changes to the program, aligning with the goals of developmental evaluation. Within a concurrent transformative design, qualitative and quantitative data are collected during the same data collection period and may have equal or

unequal priorities. For the purposes of this research project, the qualitative data provides more in-depth analysis of the patient and provider experiences during the implementation process and evaluation phase. The integration of the qualitative and quantitative occurs during the analysis phases (Creswell et al., 2003). A social constructivist stance was taken throughout the research project with an emphasis on understanding the participants' experiences, where the reality is co-constructed with the participants (Ponterotto, 2005). Within a social constructivist stance, it is believed that multiple constructed realities exist, rather than one single reality, and this is influenced by the situation, experience, perceptions and interaction between the participant and the researcher (Ponterotto, 2005). Findings were constructed jointly between the researcher and the participants through the interview questions, as well as in subsequent information arising through conversational dialogue and observation.

6.3.2 Ethnographic Approach

This study was guided by established principles for ethnographic research (Morse, 1994; Roper & Shapira, 2000). This approach allowed the researcher to use in-depth interviews, participant observation of interactions, and an examination of documents such as the screening and referral documents to study care coordination processes for older adults in primary care. Ethnography research allows the researcher to present the work in a descriptive or interpretive way, which is heavily based on the researcher "being there" (Van Maanen, 2004).

Development of Interview Guides

Interview guides were created to include a range of questions regarding the coordination of care, referral processes, engagement of patients, and experiences of patients, caregivers, and health care providers. For this phase of the project, three individual interview

guides were created: 1) health care provider interview guide; 2) patient interview guide; and 3) family caregiver interview guide (Appendices E-G).

6.3.3 Sampling and Recruitment

Purposeful sampling was chosen as the approach for the qualitative data collection and was completed between June 2015 and December 2015. It was important to gather the perspectives of persons from the primary care teams who were administering the screening tool and referring older adults to services (e.g. nurse, social worker, care coordinator). This work was completed in two Family Health Teams, a rural site and an urban site. The estimated sample size for this phase of the study was 4-6 individuals per study site, following common qualitative procedures (Denzin & Lincoln, 1994), however data collection ceased when no new information was gathered.

A health care provider at each study site served as a “gatekeeper”. A gatekeeper is an individual or group who acts as an “internal contact for the researcher” in order to direct the researcher to suitable and willing participants (see Appendix I for script). The ‘gatekeeper’ informed patients about the study and requested permission for the researcher to contact them. Participants were approached by telephone within 48 hours of their physician visit. If the participant was interested, a letter of information was provided (in-person or by email) and consent was obtained before the interview began (Appendix J). Older adults who represent different levels of risk (identified by the risk stratification tool) were sampled, using a stratified purposeful sampling technique where individuals are sampled from different health care settings (urban and rural) and by risk level. Interviews were conducted with 6 patients (2 from the rural site and 4 from the urban site).

Caregivers were also recruited to share their experiences (see Appendix K for Letter of

Information and Consent Form). Permission to contact caregivers was to be obtained from patients before connecting with the caregiver. Only one caregiver was available to participate during this study time period.

Inclusion criteria included the following: a) Health care providers: any provider at either site who is willing to participate in individual interviews and observations; b) Patients: Participants were older rostered patients at one of the two study sites (an age of 70 years or older was suggested as an appropriate cut-off for use of the screening tool, based on existing research (Morley et al., 2013); during the study one site also recruited a number of younger (age 65-69) patients for whom they felt screening was indicated); c) Caregivers: Patients gave permission for their caregiver to be contacted and involved in the research project. There were no exclusion criteria for the study sample. Stratified purposeful sampling was used for providers and patients.

The AUA was administered using paper forms allowing for analysis of specific questions (unavailable if the app version is used) and an indication of the score and referral plan (including recommendations for self-management, and community and specialist referrals).

6.3.4 Data Collection

Qualitative Data

Health Care Providers: Individual interviews were conducted with primary care and community care providers. Individual interviews were conducted face-to-face or by telephone and lasted 60-90 minutes in length. The interviews were audio-recorded and transcribed verbatim. In order to guide and assist the interviewer, an interview guide was created and consisted of questions that would enable the researcher to gain a better understanding of the

provider experiences using the screening tool and referral mechanism, and of community care provider experiences when a referral is made. Interviews were conducted over an eight month period, some providers were able to be interviewed about their experiences after a few weeks of use and others after a few months of using the tool and referral mechanism.

Patient and Caregivers: In-depth, semi-structured, face-to-face interviews were completed with patients and a family caregiver to capture individual perspectives. Two interviews were completed with each patient and family caregiver (if available). The first interview took place within a week of the AUA being administered at the clinic, and the second interview took place two months later to assess subsequent experiences. Specific attention was placed on the perceptions of engagement in care decision-making and thoughts around the process of screening and being referred to services.

Ethnographic Observation and Field Notes: Observations were completed when feasible and appropriate (Morse, 1994; Hammersley & Atkinson, 1995). Field notes were written when observations and interviews were completed (Appendix L). Entries were dated, and began with a narrative of what was observed and heard. The field notes include as much detail as could be recalled. Each entry concluded with a brief reflection.

Quantitative Measures

Assessment Urgency Algorithm (AUA): The AUA is a brief decision-tree algorithm that can predict levels of service need based on classifying patient risk levels as low, moderate, or high (Appendix N) . Low-risk patients (AUA scores of 1-2) may benefit from supports for self-management and prevention; medium-risk patients (AUA scores of 3-4) may benefit from more detailed assessment, and referrals to community services; and high-risk patients (AUA

scores of 5-6) may benefit from a more comprehensive assessment and specialist referral. The AUA is a short instrument covering cognition, activities of daily living, caregiver support, self-reported health and mood, stability of conditions, and shortness of breath.

Procedure: The AUA was completed on all patients 70+ years who came to the clinic during the study period (the AUA was also completed for younger patients (65-69) if the nurse felt a patient they would benefit from screening). At each clinic a nurse or medical office assistant completed the AUA using the electronic version that was embedded in the electronic medical record. After the AUA was completed, the form was printed and placed in a folder for the researcher to obtain every 2 weeks for data analysis.

Sample Size Calculation: The AUA was administered using paper forms allowing for analysis of specific questions and an indication of the score and referral plan (including recommendations for self-management, and community and specialist referrals). A sample of 88 AUA forms at each site was calculated based on preliminary data suggesting that there is a 50/50 split (50 % of patients are in a higher category (3+) and 50% of patients are in a lower category) at 95% confidence with a sampling error of $\pm 10\%$ (Dillman, 2000).

Caredove: Depending on the AUA score and the patient's specific situation, a referral may have been made using Caredove, an online referral platform. Once a month a report was obtained indicating the number of referrals completed by each study sites. Caredove allows the provider to search for services based on AUA score or type of service. Caredove provides descriptions about the service including wait time, cost, and eligibility criteria.

Canadian Institute for Health Information (CIHI) Attributes of Primary Care: Provider

Survey: The Canadian Institute for Health Information (CIHI) Attributes of Primary Care: Provider Survey (2013) was distributed to primary care providers at each study site at the end

of the study. The *CIHI Provider Survey* is a self-reported measure to be completed by health care providers. It was developed with extensive stakeholder input, and questions drawn from existing validated measures (CIHI, 2013). The survey considers health care provider roles, responsibilities, skills, satisfaction, collaboration and team functioning, and coordination with other services and providers. Primary care team members (nurses, physicians, pharmacists, etc.) were asked to complete the survey and place the completed survey in an envelope in the Executive Director's office. This survey was used to understand if the implemented care coordination process had any effect on team functioning, coordination or satisfaction.

6.3.5 Data Analysis

Qualitative Analysis:

The data were analyzed using emergent coding techniques (Lofland et al., 2006) where the perspectives of the patients, their caregivers and the primary care teams and community care providers were considered. Individual interview data, documents, observations and field notes made up the material necessary for thorough data analysis. The analysis (Lofland et al., 2006) began with line-by-line reading of the text. Initial coding was followed by focused coding of patterns, and interesting concepts, with analyses conducted in NVivo 10 (QSR, 2010). When the coding was complete, a clustering technique was completed to group codes into *themes* (Lofland et al., 2006; Conklin et al., 2011; Braun & Clarke, 2006). Each cluster has a name, indication of subthemes, illustrative quotations from the data, and a list of codes that support the theme.

Special attention was given to similarities and differences between the urban location and the rural location.

Quantitative Analysis:

AUA forms for each participant and associated care pathway were analyzed.

Descriptive analyses provided information on the number of people screened at each risk level, and the associated referral that took place.

The CIHI provider surveys were collected from each study site and data entered into SPSS 23 (IBM Corp., 2015) software. Data were analyzed to provide descriptive results of the current state (November, 2015) of primary health care teams in terms of team function, provider satisfaction, etc. The provider survey includes questions with both categorical and continuous response options. Descriptive statistics included frequencies, means and standard deviations. Pre (completed in phase 1) and post comparisons of categorical data were completed using unpaired t-test statistics. Survey responses remained anonymous.

Prior to completing the analysis, the researcher used the information provided through the qualitative interview data, and linked the emergent themes with the survey domains that were predicted to show change following the implementation of the AUA and the Caredove process.

The questions that were anticipated to show change included questions related to providers communicating care plans; time spent with patient; care coordination and collaboration; and efficiency of referrals to specialty services.

Sub Project – Goal Attainment Scaling (GAS) Feasibility Project

For older patients with multiple health and social concerns, there is limited consensus on which outcomes are appropriate or which standardized tools should be used for their measurement (Stolee, 2010). Goal Attainment Scaling (GAS, Kiresuk & Sherman, 1994) is

an individualized patient-centred measure which has been found to having promising applications in geriatric care planning and outcome measurement (Stolee et al., 1992; Stolee, 2010). In the application of GAS, a “follow-up guide” is developed for each patient; this includes individualized goals that are important to the patient, with each goal scaled on individualized 5-point scales representing levels of possible outcomes. GAS has been found to have strong inter-rater reliability and construct validity (Stolee et al., 1992; Stolee et al., 1999) and to be highly responsive to clinically important change (Rockwood et al., 2003, Stolee et al., 1999).

While the focus of this study was on processes of care than on patient outcomes, there was an opportunity to explore the feasibility of GAS as an outcome measure, both to assess its potential for use in future research and to yield insights into the outcomes that would be relevant for older primary care patients. This was done for several patients. During initial interviews, these patients would be asked questions such as; “*Do you have any specific goals?*”, “*What would it look like if you achieved this goal?*”, “*How would you currently rate yourself on this goal?*”. Based on the answers to these questions, the researcher completed a GAS guide which was then used in follow-up with patients during the second interview, asking questions such as; “*During our last meeting you identified {goal} as being important, could you please tell me how that is going?*”.

Ethical Considerations:

Ethics clearance for this study was obtained from the University of Waterloo’s Office of Research (ORE #20452; Appendix M). Prior to each interview, participants were briefed about the purpose of the study, the presence of the digital recorder, and the right to withdraw

participation or data at any time. All participants were notified of the confidentiality and anonymity of their responses. Real names have been replaced by pseudonyms.

6. 4 Results

6.4.1 Assessment Urgency Algorithm & Care dove Referrals

The AUA was collected on 512 patients from the urban (n=452) and the rural (n=60) sites. The data below is presented separately for each study location.

Urban Study Site

Of the 452 individuals screened at the urban study site, 58% were female and 42% were male. The average age of patients screened was 78 years old (range: 70-96). 63% of individuals were aged 70-79; 34% of individuals were aged 80-89; and 3% of individuals were 90-96 years of age.

Figure 6.2 illustrates the proportion of patients in each risk level (ranging from level 1 – 6); Table 6.1 displays the percentage of patients stratified into 3 categories - low, moderate and high. Seventy per cent of individuals were screened at low risk (AUA 1 and 2); 25% were screened at moderate risk (AUA 3 and 4); and 5% were screened at high risk (AUA 5 and 6).

Figure 6.2. Proportion of Patients by Risk Level (Urban)

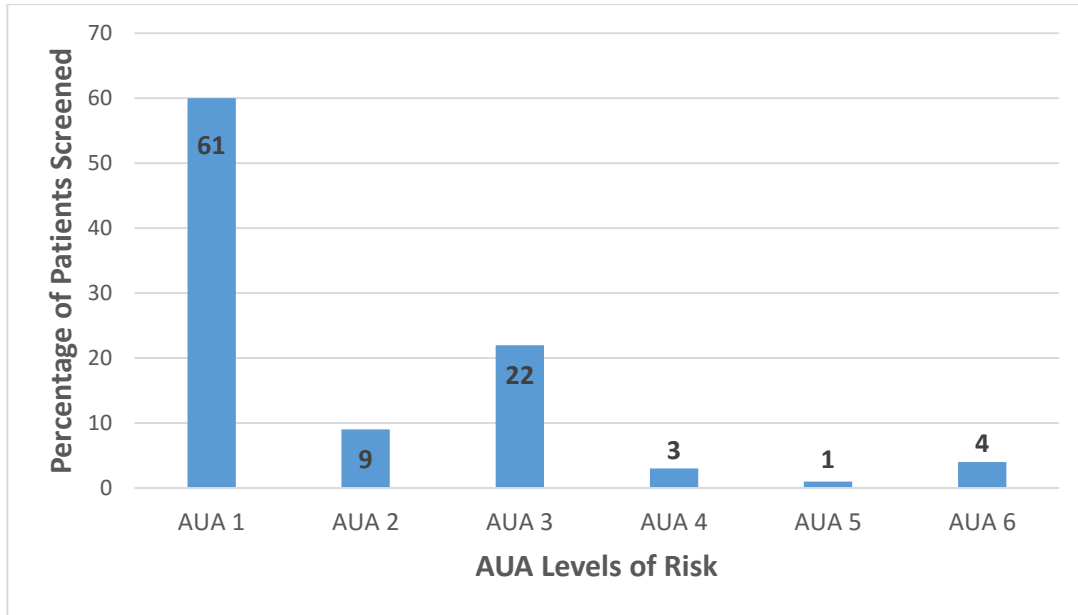


Table 6.1. Percentage of Patients in Each Risk Category

Risk Category	Percent
Low Risk (1-2)	70%
Moderate Risk (3-4)	25%
High Risk (5-6)	5%

Rural Study Site

Of the 60 individuals screened at the rural study site, 58% were female and 42% were male. The average age of patients screened was 79 years (range: 64-93). 12% of individuals were between 64-69; 42% of individuals were between 70-79; 40% of individuals were between 80-89; and 7% of individuals were between 90-93 years of age.

Figure 6.3 illustrates the proportion of patients in each risk level (ranging from level 1 – 6); Table 6.2 displays the percentage of patients stratified into 3 categories, low, moderate and high. 58% of individuals were screened at low risk (AUA 1 and 2); 32% were screened at moderate risk (AUA 3 and 4); and 10% were screened at high risk (AUA 5 and 6).

Figure 6.3. Proportion of Patients by Risk Level (Rural)

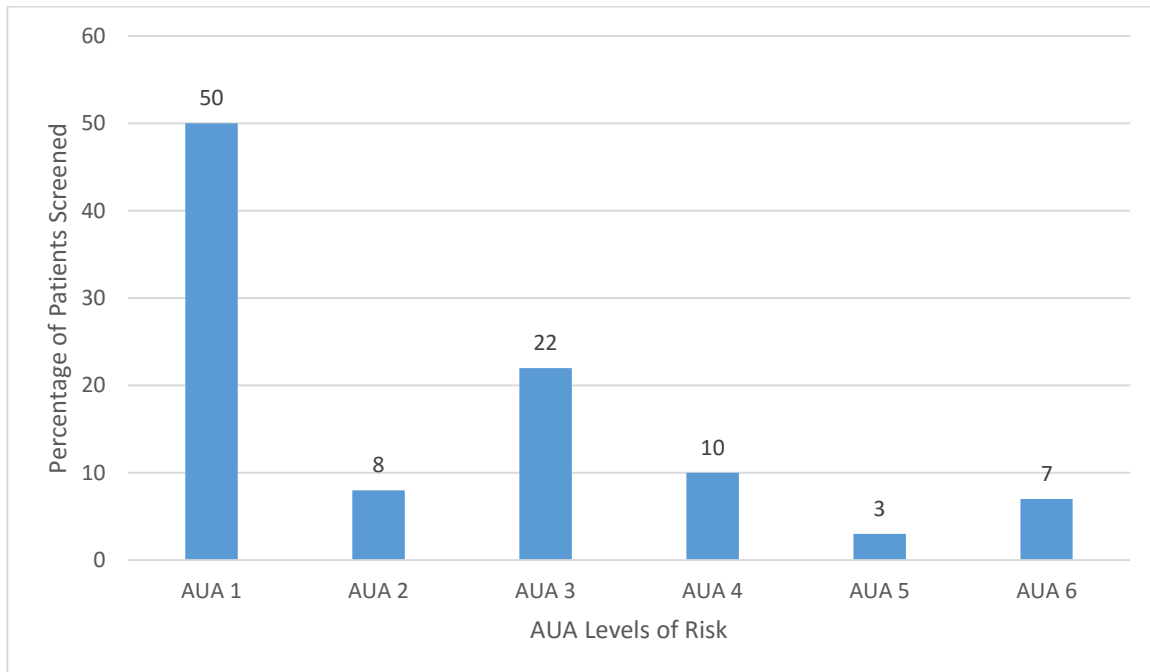


Table 6.2. Percentage of Patients in Each Risk Category

Risk Category	Percent
Low Risk (1-2)	58%
Moderate Risk (3-4)	32%
High Risk (5-6)	10%

For those individuals screened, referrals were made, if appropriate, to community services using the online referral mechanism, CareDove. In total, 24 referrals were made with the many of these referrals (30%) being for housekeeping services. Figure 6.4 and 6.5 illustrate the number of referrals made to a variety of community services from the rural and urban site, respectively.

Figure 6.4. Rural Site: External Referrals by Service

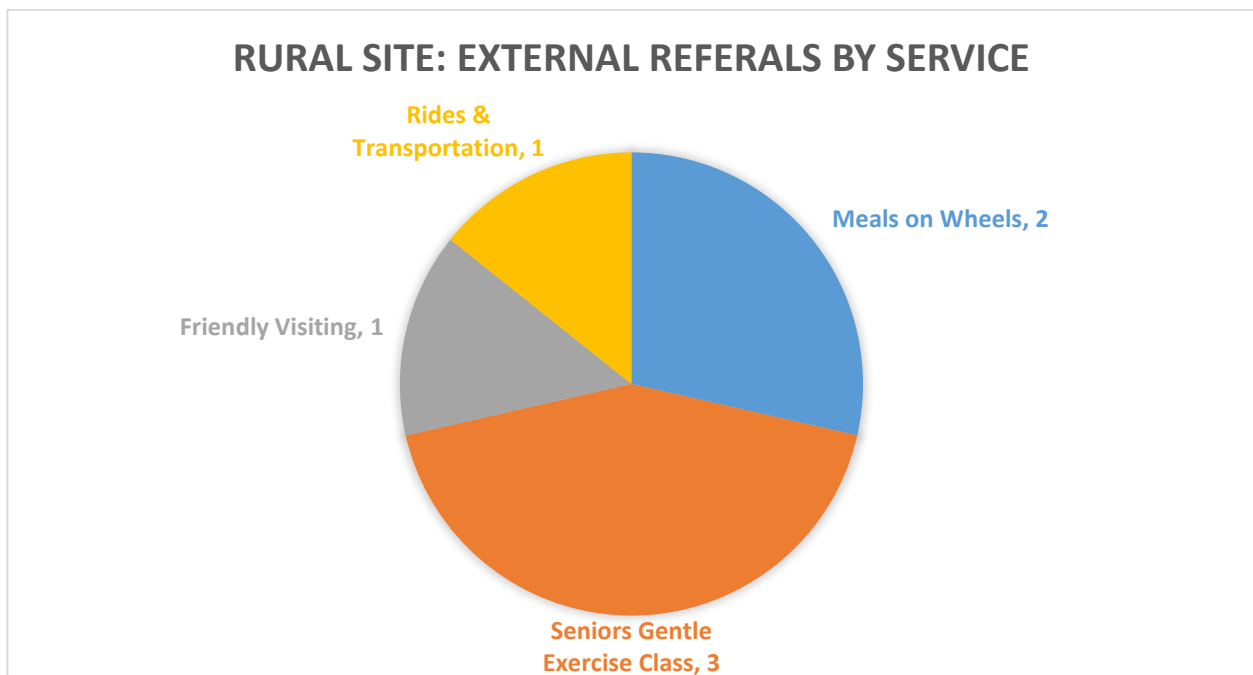


Figure 6.5. Urban Site: External Referrals by Services

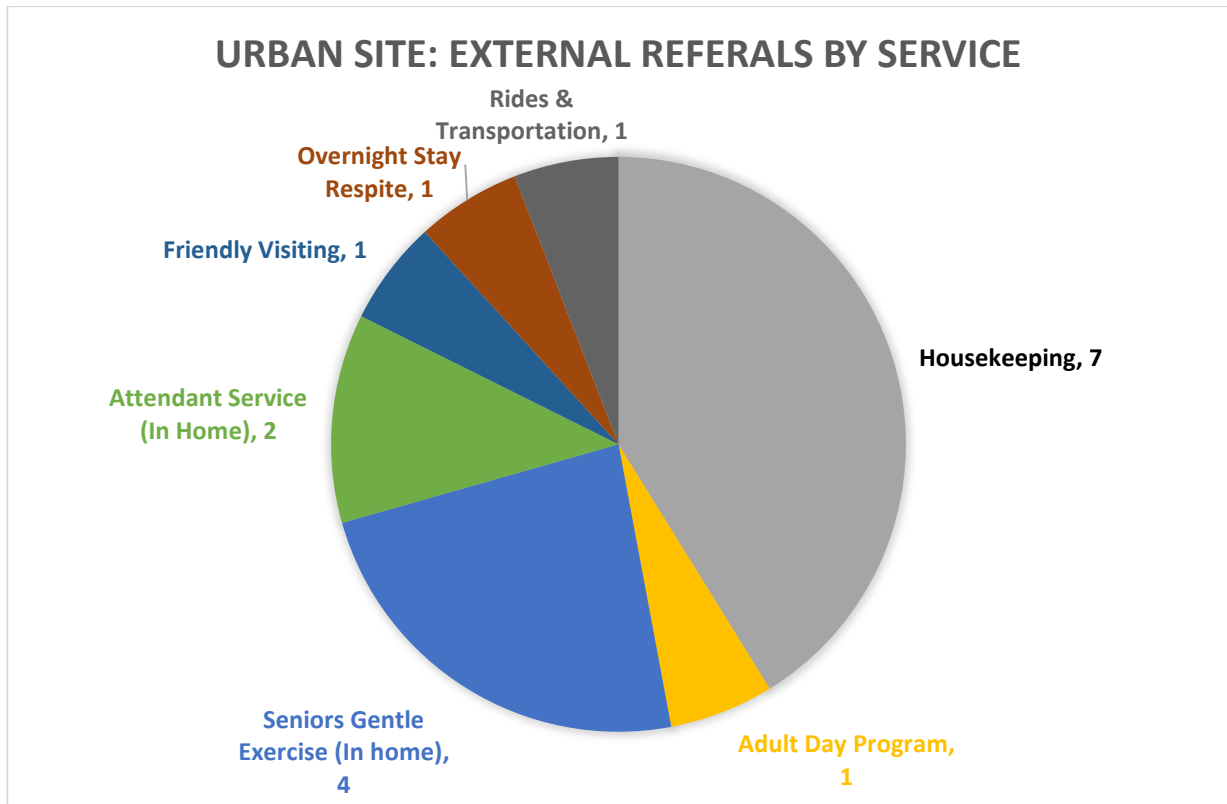


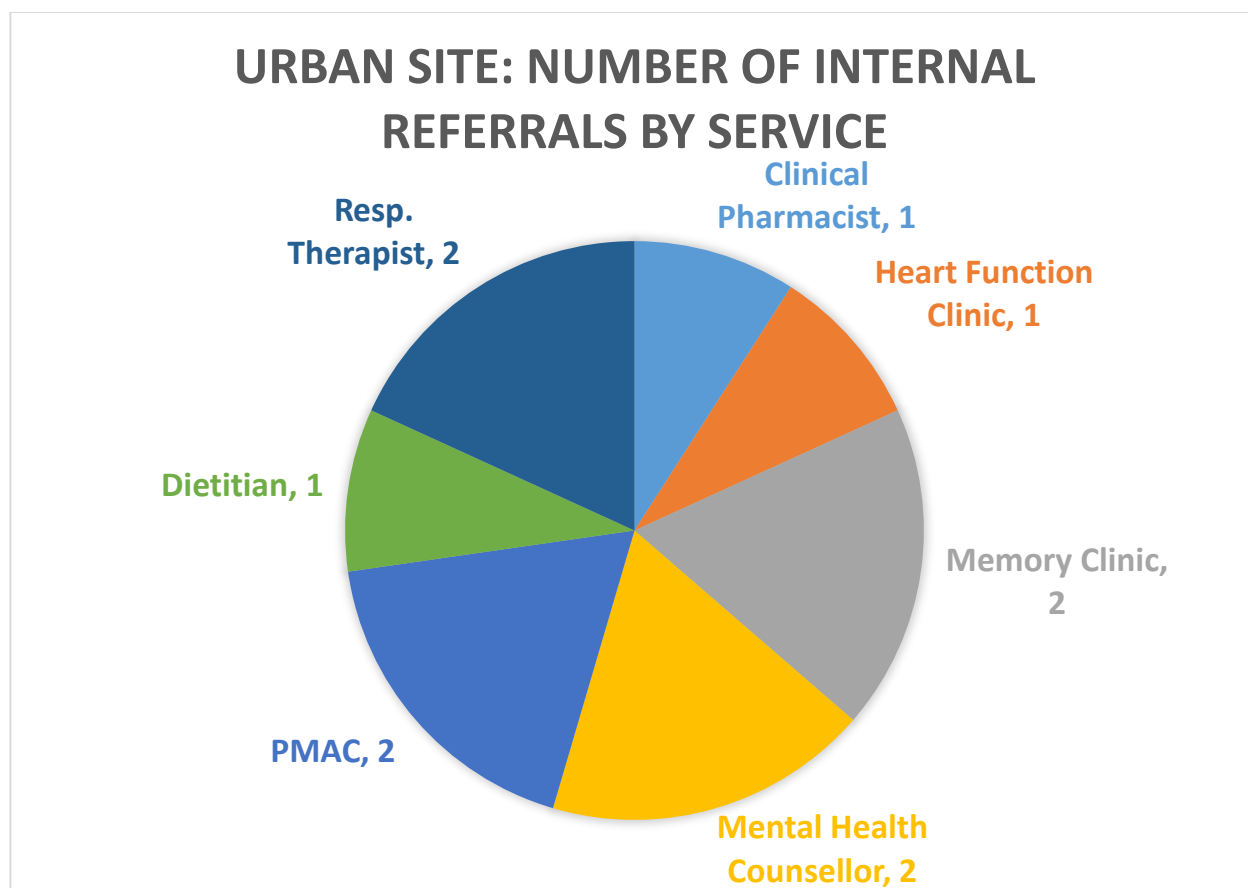
Table 6.3. Carerove referrals as a result of AUA screening

Date Referred	Wait Times (days)	Appointment Date	Service Selected	Location	Outcome (if identified)
2015/05/05	1	2015/05/06	Meals on Wheels	Phone	Admitted
2015/06/05	3	2015/06/08	Meals on Wheels Friendly Visiting	Phone	Admitted
2015/07/09	1	2015/07/10	Gentle Exercise	Phone	Admitted
2015/07/14	40	2015/08/24	Housekeeping Gentle Exercise (In-home)	Home Visit	Waitlisted
2015/07/22	20	2015/08/11	Adult Day Program Overnight Stay Respite	Phone	Waitlisted
2015/07/23	7	2015/07/30	Gentle Exercise (In home) Housekeeping	Home Visit	Waitlisted
2015/08/06	25	2015/08/31	Gentle Exercise Class	Phone	
2015/08/11	32	2015/09/09	Housekeeping	Home Visit	
2015/08/13	5	2015/08/18	Gentle Exercise Class Transportation	Phone	Waitlisted
2015/08/27	142	2015/09/08	Attendant Service (in home)	Phone	
2015/09/01	14	2015/09/15	Attendant Service (in home)	Phone	
2015/09/02	1	2015/09/03	Gentle Exercise (in home)	Home Visit	Admitted
2015/09/03	15	2015/09/18	Friendly Visitor	Phone	
2015/09/03	32	2015/10/05	Housekeeping	Home Visit	
2015/09/18	8	2015/09/25	Rides & Transportation	Home Visit	
2015/09/29	6	2015/10/05	Gentle Exercise (in home) Housekeeping	Home Visit	Waitlisted
2015/10/05	15	2015/10/20	Housekeeping	Home Visit	Waitlisted
2015/10/27	5	2015/11/02	Housekeeping	Home Visit	Waitlisted

The table above, Table 6.3, displays the date the referral was made, the appointment date, the service, and in some cases the outcome of the appointment. The average wait time for an appointment was 12 days, with the shortest wait time being only one day and the longest wait time being 29 days. The 29 day wait time was due to an error on behalf of the community organization who overlooked the referral.

A number of referrals were also made internally to services that were offered by the family health team. These data were only available from the urban family health team. Figure 6.6 illustrates the internal referrals that took place as a result of the AUA scoring.

Figure 6.6. Internal Referrals in the Urban FHT



Reasons why referrals to services were not completed

Among the 512 patients who were screened, there were a number of individuals who had an AUA score 3 – 6 who would benefit from extra supports, however no referrals were made. Health care providers provided information on the bottom of the screening form that explained why referrals were not completed. Table 6.4 displays all of the reasons why a referral was not completed.

Table 6.4. Reasons for decisions not to make a referral

<ul style="list-style-type: none">• Reasoning section left blank• Patient has caregiver providing support• Community Support Services or CCAC already in place• Managing well in current situation, patient doesn't want support• Lives in retirement home where extra support is provided• Has both caregivers and services in place already• Took information home to consider different options• Discussion concerns with doctor (referral may be made as a result)

Unfortunately, the referral information on many forms was left blank (n=166) however this was mainly for individuals who scored an AUA of 1 and were managing well, and another 139 forms identified that the patient was managing well in current situations. Of those individuals who scored higher, 45 forms identified that caregiver support was being provided and 48 forms indicated that the patient was already on services. Other reasons included that the patient was taking information home to think about options (n=19) or patients were discussing concerns with the physician (n=18) and as a result a referral may have been made by the physician (this was not captured).

6.4.2 Qualitative Results

Patient and Caregiver Experiences

Following the implementation of the AUA risk-screening tool and the referral process using Caredove, interviews were conducted with patients and if available, family caregivers. Initial interviews were conducted with six patients and one caregiver following their doctor's appointment at the primary care clinic. Three month follow-up interviews were completed with four patients and one caregiver. Table 6.5 describes each participant, their AUA score, types of referrals made and whether caregiver support was available. The mean age of participants was 79.2 years old (range 66-88), and participants represented a range of AUA scores. Some participants had a service referral as a result of the AUA score; for others it was felt that they were managing fine and referrals were not necessary.

Table 6.5. Participant Characteristics

Code	Pseudonym	Age	AUA Score	Referral Made?	Caregiver Support?
R01_Pt	Abbey	80	1	No referral made	Lives with husband
R02_Pt	Kay	66	3	Friendship Circle; Dietitian; Education programs; Physiotherapy	Lives alone; son provides transportation when needed
U01_Pt	Sarah	85	1	In-home exercise	Lives alone; granddaughter lives in community
U02_Pt	Alice	84	2	Housekeeping	Lives alone
U03_Pt	Roger	72	6	Adult Day Program, Alzheimer Society, CCAC	Wife provides a lot of support (U03_CG)
U04_Pt	Bob	88	1	No referral made	Lives alone

The findings from these interviews revealed a number of themes related to patient and caregiver experiences with the AUA and Caredove process. After reviewing the data and applying appropriate thematic analysis, four broad themes emerged from over 70 codes. Table 6.6 describes the broad themes, key subthemes and example codes.

Table 6.6. Themes and Subthemes (Patient/Caregiver Experiences)

THEMES	SUBTHEMES	EXAMPLE CODES
1. IMPROVED AWARENESS AND EDUCATION	<ul style="list-style-type: none"> • <i>First time hearing about services</i> • <i>Lots of services available to them</i> 	<ul style="list-style-type: none"> ○ took information home ○ education ○ learning about services
2. PATIENTS FELT ENGAGED IN THE DECISION-MAKING PROCESS	<ul style="list-style-type: none"> • <i>Involved in decision-making</i> • <i>Providers spent adequate time with patients</i> 	<ul style="list-style-type: none"> ○ Engagement ○ Decision-making ○ Appointment time ○ Discussing services
3. PATIENTS SHARING INFORMATION WITH OTHERS	<ul style="list-style-type: none"> • <i>Encouraging friends to attend programs</i> • <i>Passing information to friends and family</i> 	<ul style="list-style-type: none"> ○ Conversations with people in the community ○ Broader education
4. DIFFICULTY ACCESSING SERVICES	<ul style="list-style-type: none"> • <i>Cost of Services</i> • <i>Waitlist Issues</i> • <i>Accessing Services</i> 	<ul style="list-style-type: none"> ○ Patient still on waitlist ○ Patient cannot afford services

The responses from the patients and caregiver provided information that supported the AUA and Caredove process. Within this broad theme, three subthemes emerged and are discussed in more detail below.

IMPROVED AWARENESS AND EDUCATION

Evident through many of the interviews was that the patients and caregiver felt that this process provided them with important education about the type of services in the community that are available. It was also noted that the process of learning about services and receiving information took time. The quote below indicates that participants were surprised by the various services that were available,

I was looking at all of this information and I was surprised that there were so many services that I could use – Patient

Participants recognized the value in learning about the different services in case they needed to access more services in the future. One participant below acknowledged that physicians are not always aware of the community services and appointment times are short so there is limited time to discuss service options,

I really think this process makes people more aware of the services. This gives patients access to information about so many different services which is helpful because physicians can't remember all of that information nor do they have time to discuss it with you. – U_Pt02

In order for the health care provider to offer information to the patient, a conversation had to be established between the provider and patient, which took more time. By providing this knowledge to patients, patients are now able to ask for services if they feel they need more supports, or to find out about services to which they can self-refer. Many participants felt this was the first time that this information had been provided to them and overall they felt it was beneficial.

Have they ever spoken to you about these kind of services before?

No, that was the first time...it is helpful because there are many people in my age that it could benefit. – R_Pt01

Regardless of whether a referral was actually made on behalf of the patient, participants truly felt that they had gained knowledge about services that were available for them in the community. They also commented that they now had a contact at the clinic, someone to call if they decided they wanted to access a service that they had learned about.

PATIENTS FELT ENGAGED IN THE DECISION-MAKING PROCESS

Many participants felt that the health care providers were involving them in decisions around which services to access, if a referral was needed. The quote below describes a caregiver' experience receiving services and although she feels well supported right now, she is aware of other services that she can request when needed,

Interviewer: Yes? Great! Ok. And, you talked about a lot of services, do you feel that you were involved or engaged in those decisions about which services best met your needs?

U02_CG: Yeah, they have been really good about, um, going over all the resources in the community...um, we're probably at the initial stages of, of this condition, so we haven't accessed a lot of the resources yet. I mean we do have CCAC, like a personal support worker coming morning and evenings and now a support worker coming in twice a week for three hours, uh, to give me respite... I know there are more services but we are just at the beginning of this, I know who to ask and where to go if I decide we need more help. The [provider] has been really great!

Patients who participated in an interview felt that the provider who completed the risk-screening and referral process spent adequate time walking through different service options

and discussing the benefits of the services⁵,

Oh yeah, we spent a lot time and talked them [services] over and how it might help or not help. For instance, she asked about the dietitian referral, and I said it would help because I don't currently eat well. – R02_Pt

Interviewer: Do you feel that all your questions were answered? Did you feel included in the decision-making?

R01_Pt: Yes, oh she [provider] was great! I asked my questions and she spent a lot of time walking through the options with me.

One participant, who was a retired nurse added this comment about patients being involved in decision-making,

I think the reason patients are not as involved in making decisions is simply because they don't know that they can be... - U04_pt

Overall, patients seemed to feel that they were involved in decisions around their care for this process (accessing services through Caredove).

PATIENTS SHARING INFORMATION WITH OTHERS

Participants not only discussed how they felt more educated and aware of services and resources in the community, but also that they were sharing the information with friends;

It's really good to make, uh, people aware of the services. I have passed this information on to my friends and they didn't know about these either. – U01_Pt

⁵ Caredove provides detailed information about the service including a description, the cost (if applicable) and wait time.

Interviewer: Now when we chatted before, you had said that you were trying to educate some of your friends on all of these services, how's that going?

R02_Pt: Yeah, and its working because, they're now aware of it that they can get these things, and they're asking the doctor. 'Cause the doctor can't read your mind.

Interviewer: No...

R02_Pt: And so then you're...what I call suffering in silence, even it comes to depression...so now they know to ask the doctor about these things

There are so many services, it's absolutely incredible. There's another lady here, and she's struggling a lot of the time, and I said well you know, are you aware that if, if you talk to your doctor he can have Community Care Access Centre send somebody out to assess your needs, and you might be able to get help here at the apartment. She said "Oh I can?" I say yeah. – R01_Pt

Patients felt that it was really important for more clinics to be providing this type of information because so many of their friends had never heard of many of the services. One patient shared how she was trying to help a friend who was “bored” however the friend was not interested in attending the community program,

I said “how about the friendship circle? All we have to do is sit and have tea, and laugh and talk with people. And if you want to have a bit of a walking”...she said, “No I'm not really into that kind of stuff”, well then, don't tell me you're bored. – R02_Pt

Although there are some individuals who do not wish to attend community programs or receive help from a community organization, there are a number of individuals who really could benefit from the extra help if only they knew about the services.

Overall support for the AUA and Caredove

Through conversations with the participants, there seemed to be an overall sense of support for this process in primary care. Participants were not necessarily aware that a nurse would be asking them questions when they came into the appointment, but many did not seem to mind and actually appreciated that the providers were taking extra care to ask about their health,

I'm 88 years old and manage well on my own so I don't need any services. I think this process is important for us though and now I know who to ask if I need help. – U04_Pt

I didn't know that they were doing this [assessment] at the office, but it is very good for people my age – U02_Pt

During a follow up interview, one patient wanted to express how thankful she was to have been linked up with services. She was now attending cooking classes, yoga classes, and physiotherapy and education webinars for her chronic disease. This participant shared her thoughts about keeping this program in primary care in the quote below,

This is a great way to really look after us old people. And it's now up to...the doctors and the nurses in particular...they have to make sure they refer their patients to the services, you can't make a horse drink if they don't want to, but let them know these services are available, because that's what I hear from people, is "Oh we didn't know we could go to that, we didn't know that was available". So, my only remark would be to make sure that all the doctors, the nurse clinicians, and RPNs or whatever they are, registered practical nurses, that, that they do like mine does, and says this stuff is available, are you interested in going? That's what [health care provider] did with me and I'm very thankful. – R02_Pt

DIFFICULTY ACCESSING SERVICES

Although there seems to be general support for the screening and referral process among the patients that were interviewed, there are some issues and concerns that were raised during the individual interviews. Participants were offered services that sounded like they would be helpful but when the patient inquired further, they realized that they could not afford to pay for the service (as indicated in the quotes below),

When I called to investigate, to find out, they told me I have to pay so much for the service.

He suggested someone to help me with my house cleaning, and I would have to pay for that....You see, and those are the most, important thing to me, really but it is too expensive...And uh she did give me like a different dietitian option, the different meals on wheels or you know, but again the prices of the different meals are too expensive for me. So I didn't participate in any – U02_Pt

After meeting with U02_Pt in her house, it was evident that she really could benefit from extra support including transportation and housekeeping. She stressed that she can't afford to pay for help. There may be some opportunities to have some of the services subsidized, however this was not discussed with the patient and as a result she declined the referrals. – Observation [Aug, 2015]

Another issue that arose during the interview process was the long wait time that some patients experienced when they were referred to certain services. Housekeeping and in-home exercise classes have long waitlists; for instance, according to CareDove the waitlist for homemaking is currently 12 weeks. During a follow-up interview with a participant, the researcher learned that the patient was still waiting for in-home exercise,

R1: Yes, the other lady came, uh, I can't remember her name, isn't that awful. Yes, she did come, and, but she said that the waiting list is so long, for people that are interested in the exercises.

Interviewer: Yeah, so, so have you heard anything since then?

R1: No, no.

Interviewer: They haven't contacted you, or...?

R1: No, no, I'd just decided I'd wait and, and hear.

She hadn't been contacted by the agency in over 12 weeks however she was going to continue waiting. Another participant was also disappointed to learn about the limitations of a service, for instance she could be offered one bath a week, however she felt that if she had to bathe herself the other three times a week what would be the point in having someone come in, so she declined the service.

Follow-Up Interviews with Participants

When follow-up interviews were conducted three months following the initial interviews the researcher learned about patients’ experiences with accessing the services to which they had been referred. Table 6.7 outlines the journey of each patient who participated in an interview.

Table 6.7. Three Month Follow-Up Information about Service Use

CODE	AUA SCORE	REFERRALS	THREE MONTH FOLLOW-UP
R01_PT	1	No referral made	Not available for follow-up interview
R02_PT	3	Friendship Circle; Education programs; Physiotherapy	Has attended all of the programs and went back to nurse for more referrals, such as cooking class. Patient reported she was very happy and managing well.
U01_PT	1	In-home exercise	Still on waitlist, patient reported she has fallen two times in the past 3 months with no serious injury. Spending more time being inactive
U02_PT	2	Housekeeping	Patient declined these services after learning how expensive they were. Patient reported that she would still really like help with bathing, cleaning and transportation but can’t afford to pay the price of these services.
U03_PT	6	Adult Day Program, Alzheimer Society, CCAC	Patient was just accepted into the Adult Day Program (was on waitlist); patient is receiving care from CCAC and caregiver reported that they are finally ready to look into supports offered by the Alzheimer Society
U04_PT	1	No referral made	Patient reported that he is still managing well and aware of services if he feels he needs them in the future.

Two individuals had to wait for services, one individual declined the services, one individual is still managing well and one individual has accessed a number of services. Regardless of the situation, all participants still agreed that this process was beneficial in terms of either linking them with services, or providing education on services and resources that were available for them, should they wish to access them in the future,

It's been fantastic, and my advice if, if I was to give advice to the government, is to make more of this available - R04_Pt

Goal Attainment Scaling (Sub-Project)

GAS guides were created from the available interview data for three participants. The table below (Table 6.8) outlines example goals from each patient.

This table illustrates the potential impact coordinated care could have on patients individualized goals. For instance, the patient who was referred to services in the community, improved on both of her personal goals. The individuals who were not receiving services for different reasons (cost, waitlist) did not have the same outcome.

Table 6.8. Goal Attainment Scaling Guide⁶

ATTAINMENT LEVELS	U_PT1 WALKING	R_PT2 NUTRITION	R_PT 2 PAIN MANAGEMENT	U_PT2 DAILY ACTIVITY
MUCH LESS THAN EXPECTED -2	Walk laps around building 1-2x/week*	Balance dinner 1-2x/week	Does not have knowledge to self - manage pain (daily pain) ✓	Activity once/ week with rest
SOMEWHAT LESS THAN EXPECTED -1	Walk laps 3-5x/week✓	Balanced dinner 3-4x/wk ✓	Has obtained very limited knowledge about self-managing pain (pain often)	Activity 2-3 times /week (with rest) ✓*
EXPECTED LEVEL (PROGRAM GOAL)	Walk 1-2laps daily	Balanced dinner everyday	Has obtained some knowledge to self-manage pain (pain sometimes)	Activity 4-6 times/week (with rest)
SOMEWHAT BETTER THAN EXPECTED +1	Walk 3-4laps daily	Balanced dinner every day and lunch 2-3x/week *	Has obtained lots of knowledge to self-manage pain (pain rarely) *	Activity daily (with rest)
MUCH BETTER THAN EXPECTED +2	Walk >4 laps daily	Balanced dinner and lunch every day	Has obtained sufficient knowledge to self-manage pain (pain not at all)	Activity with no rest
COMMENTS	1 st Interview: On waitlist for exercise program 2 nd Interview: has fallen several times since first interview	1 st Interview: referred to dietician and cooking classes 2 nd Interview: loves the cooking class and learned how to cook for one person	1 st Interview: education referral for fibromyalgia pain 2 nd : attended education sessions and physiotherapist referral	1 st Interview: needed help with exercise but couldn't afford services 2 nd : Still needs assistance

⁶ Table Legend: ✓ indicates where the patient started; * indicates where the patient was at the second interview

Health Care Provider Experiences

Following the implementation of the AUA risk-screening tool and the referral process using Caredove, interviews were conducted with health care providers in the primary care clinics. Interviews were completed with seven health care providers from the urban (n=4) and rural (n=3) sites. Interviews were also completed with four care providers who provided community services to patients from the primary care clinics. Table 6.9 provides a description of each participant.

Table 6.9. Participant Descriptions

Participant Code	Site
991_R_RPN	Rural
992_R_RN	Rural
993_R_RN	Rural
994_U_RN	Urban
995_U_MOA	Urban
996_U_MOA	Urban
997_U_MOA	Urban
998_C_FP	Community
999_C_FP	Community
101_C_M	Community
102_C_M	Community

These findings revealed a number of themes related to provider experiences with respect to the AUA and Caredrive process. After reviewing the data and applying appropriate thematic analysis, seven key themes emerged from over 100 codes. Table 6.10 describes the broad themes, subthemes and example codes.

Table 6.10. Themes and Subthemes (Health Care Provider Experiences)

THEMES	SUBTHEMES	EXAMPLE CODES
1. INTEGRATION OF PROCESS INTO CURRENT PRACTICE	<ul style="list-style-type: none"> • <i>Current Workflow</i> • <i>Health Care Provider process for screening</i> 	<ul style="list-style-type: none"> ○ AUA Process ○ Completing AUA ○ Using Caredove
2. BUILDING RELATIONSHIPS WITH PATIENTS	<ul style="list-style-type: none"> • <i>Conversations with patients</i> • <i>Engagement in decision-making about services</i> 	<ul style="list-style-type: none"> ○ Conversation ○ Engagement ○ Relationship building
3. KNOWLEDGE ABOUT SERVICES IN THE COMMUNITY	<ul style="list-style-type: none"> • <i>Education</i> • <i>Information about services</i> • <i>Caredove</i> 	<ul style="list-style-type: none"> ○ Using Caredove ○ Spending extra time learning about services ○ Service options
4. “IT DOES FLAG PEOPLE”	<ul style="list-style-type: none"> • <i>AUA Score</i> • <i>Assessing older adults</i> 	<ul style="list-style-type: none"> ○ Age for AUA ○ Asking the AUA questions ○ Physician asking AUA score
5. COORDINATION TAKES TIME	<ul style="list-style-type: none"> • <i>Conversation takes time</i> • <i>Appointment time needs to be longer</i> 	<ul style="list-style-type: none"> ○ Conversation takes time ○ Caredove Fax form
6. ACCESSING SERVICES	<ul style="list-style-type: none"> • <i>Waitlist</i> • <i>Cost of Services</i> 	<ul style="list-style-type: none"> ○ Too many options for patients ○ Provider struggling to choose service
7. IT’S ONE WAY COMMUNICATION	<ul style="list-style-type: none"> • <i>Communication with community care</i> • <i>Information Sharing</i> 	<ul style="list-style-type: none"> ○ Communication with community services ○ Getting information back ○ Caredove issues

INTEGRATION OF PROCESS INTO CURRENT PRACTICE

The health care providers gave detailed descriptions of the process they followed when a patient was taken into an examining room. All of the providers who were interviewed described a very similar process, similar to that described by a nurse, below,

In the morning, we screen the patient list and make a little note beside each patient's name to do the AUA. Usually we bring our patient in and we take care of what they're here for first, because we have to get that in case we don't have time to do the AUA, at least what they're in for is done first and blood pressure, and then we say to them "we are asking patients some questions that help us better suggest services for you." Most of them say yes, we've had a few people say I'm not interested. If they are in the higher category, it is in the patient chart so the physician can also see it. We show the patient the Caredove site and go through different services that might help them. We either make a referral or give them information. If a referral is made we have to fax a separate form. At the end we print the AUA screening and place it in a folder at the nurses' station for you to collect.

The screening and referral process was implemented into care settings in a way that would limit the impact on daily practice. Nurses felt it was feasible to complete the screening tool when they first brought the patient to the room. If the clinic was understaffed for the day, or time was limited, the nurses said they were unable to complete an AUA on every patient.

BUILDING RELATIONSHIPS WITH PATIENTS

Through the interviews with health care providers it was evident that many found the screening and referral process beneficial for a number of reasons. First, health care providers discussed how the screening questions facilitated open and honest conversations between the patient and provider,

It opens up a lot of discussion and I think it makes people more honest about what their needs are... A lot of our seniors have privacy issues, or "I'm okay" and they don't want people to worry about them, so I think there's a couple things happening...we can be more aware of what's really going on and I don't know, it just seems like, again, that supportive environment, and I think people are more honest about what they need – Nurse

Sometimes patients say that they are managing well, however when the patient is engaged in a discussion about their activities of daily living and asked to report how they are feeling, the provider may start to learn more about the patient. Based on this information, providers felt that they were better able to link the patient with services and support. Providers also discussed how this process led to a relationship where the patient has a point of contact at the clinic if they need anything,

It empowers our staff to make a difference in people's lives. Especially with the Caredove, taking the time to go on there with the patient, and I think it's forming connections and relationships, I think it's nice for those patients down the road if they have a question, they remember that staff member who took the time to do it with them, and ask them questions, or follow up with them. So that's nice – Nurse

Lastly, providers felt that they got to know a little bit more about the patients (as described in the quote below). Rather than the typical "what are you in for"; the screening tool opened up discussions about their life and what was going well and where there might be some issues.

We get to know them [patients] a little bit more because of the questions...most of them kind of talk about their life and that kind of thing, which helps me to figure out what maybe options are for Caredove and that kind of thing. – MOA

The process really allowed for conversations with the patients, and health care providers acknowledged the benefit of this not only to the patients feeling more comfortable but also to the provider who learned more about the patients and their situation.

KNOWLEDGE ABOUT SERVICES IN THE COMMUNITY

During the interviews, providers also acknowledged the benefits they personally experienced as a result of the implementation of the screening and referral tools. Providers were not aware of all the services in the community that could assist their older adult patients. Providers did state that they were familiar with the common referrals such as CCAC or the Adult Day Program for persons with dementia, however they were not as familiar with the community support service sector or the services for chronic disease management. This is described by a participant below,

There was never any kind of community supports really offered before, unless it was like, you go to [Adult Day Program] and then you're under that umbrella, for a day program and that sort of thing. But there was never a time where we could help them with housekeeping, get private care or... it's just made us realize how much support there is in the community for these people. – Nurse

Providers were surprised by the number of services that were available in the local community. One provider spent time browsing through the website whenever she had time during the day,

I have been sitting on the website every once and awhile when I get a few minutes to look at it. I didn't even realize that they can get a phone call once a week to see how they are doing and all that kind of stuff, which is great for someone who maybe doesn't want someone to visit but a phone call or something like that, I thought "Oh my god wow, like they even have that!" ...so I've looked at it just to see what options are out there – MOA

Participants appreciated having access to a site where they could browse services geared towards the individuals level of risk. Although the providers felt this was extremely helpful for coordinating care, some said that at times the number of options were overwhelming both to themselves and to the patient.

“IT DOES FLAG PEOPLE”

Lastly, some providers felt that the screening tool was helpful in identifying individuals who needed extra help. At first, providers were not sure if a tool was necessary because they know some of their patients so well. After using the tool for a while, one provider said,

I would say it [the AUA] does flag people, because when you're going through you're thinking "oh I think they're managing", but that's actually not the case.....so this helps to make sure the patient has the right support" – Nurse (Urban)

Although the use of clinical judgement is the most important, the tool does help to identify individuals who are in urgent need of a more comprehensive assessment or service referrals. Providers who are using the tool see the value in it, and have said that they have identified some patients in the moderate-high risk category who they previously thought were managing well. Furthermore, physicians in the clinic who support the use of the tool are asking the nurses for the AUA score before going in to see the patient.

Although there were a number of benefits identified by providers, there were some barriers identified as well.

COORDINATION TAKES TIME

The first issue, identified by many of the providers, was the issue of time. Providers commented that the screening tool was very quick and easy to complete, however the conversations that arose as a result of the screening took time.

*Always the time part is important. If there's some way to get a little bit more time, and I think it's not really the questionnaire that's the problem, it's figuring out the CareDove part if needed. So finding out, just booking those appointments, because they do take that extra time because you have a conversation, then have to fill out everything on the computer and then you have to fill out a fax form and then faxing that off and then making sure it gets sent out. That I find is more time consuming –
MOA*

The conversations that arise as a result of the tool are important for figuring out which services would be most beneficial to the patient in their specific situation. One provider felt that sometimes the screening tool can take more time depending on the patient. For instance, if the patient was asked to report their health, they may share a story about how they are feeling before answer the question.

DIFFICULT FINDING APPROPRIATE SERVICES

Another major barrier that emerged through the interview process was an issue with the CareDove referral mechanism in terms of trying to link patients with services. A specific situation is shared by a provider in the quote below,

My challenge with CareDove, and I will use an example, one of the gentlemen I see is suffering from grief and depression. His wife died about 3-4 years ago, and it is causing other issues. So I went on to CareDove thinking I am going to send him somewhere, problem is, and closest place on CareDove is [rural town]. This gentleman's means of transportation is a scooter, he can't make it to [rural town]. So then I had to be creative to see what I could find within a scooter distance of his

building for him to be able to go to. So it's called Friendship Circle, which is run by one of our senior programs, and I try to link her with him to see if we can get him coming in. So that is one of the challenges I'm having is that the clients that I'm seeing, some of them don't have licenses and they don't have vehicles. - Nurse

Searching for services becomes difficult in a rural community where there are limited service options and a lack of transportation. Another issue with accessing services is the issue of cost for patients. One provider said,

I think the biggest driving factor in our demographic is whether or not they have to pay for services, absolutely whether or not they will accept help often comes down to whether or not it's covered. So being able to search based on that will be very helpful - Nurse

Providers suggested that Caredove add in special search option features that allow the provider to search for services that are free to access, as well as services that do not have a waitlist. One provider said,

I think even just the more we use the Caredove, the better you'll get at it, and the more comfortable we'll get at it, so I think it's just time, it's going to take a bit more time to keep it rolling. – Nurse

So although there were some difficulties experienced with Caredove, some providers felt that the longer they use the website, and the more time they spend looking at the different services, the more comfortable they will become.

Other Barriers

Lastly, a provider wanted to acknowledge that although more patients open up and become honest about issues, there are still going to be individuals who will minimize their ADL

limitations for fear that they will be taken out of their home or lose their license to drive. This is described by a provider in the rural community,

A barrier as well that I do think sometimes... there are things they do not wish to tell a lot of us, and then I feel bad because they're probably missing out on some of those services because they don't know that it's not going to affect their [driver's license] in most circumstances. Aging is harder than we realize at times, somebody has been extremely competent their whole life, raised families, juggles many things and then simple tasks become challenging. It's overwhelming, and there's such a fear when you live rural, there is no public transportation, so that license is huge, and the living situation, if you've lived in the country, you have a lot of older people who are struggling in their homes, they're not laid out well, we're concerned for their safety, but that is their choice and as long as they're competent we need to support those choices, but sometimes with things like this they're going to minimize things, because they fear that the eventuality would be being told they might need a nursing home or being told they might not be able to drive – Nurse

These are important considerations moving forward. Some of these barriers can be addressed through modifications with the Caredove site. Larger system changes would be needed to address other issues, such as time constraints.

IT'S ONE WAY COMMUNICATION

Through this process, there were some broader system issues identified. Although primary care teams were making connections with community care through Caredove, community care providers were unaware that an AUA had been completed with the patients. As a result, community care was often conducting a re-assessment that may not have been necessary. Interviews with community care providers identified that this was still an area that needed to be improved,

When I look at the referrals from the family health team, there is nothing on this booking that says they went through uh, an interRAI screener already – Community Care Provider

The interviews with community care representatives suggested that they would really appreciate knowing that a screener was completed and this information would help to speed up their process of putting the patient on appropriate services,

I do think it should be in primary care as long as the person who's implementing and putting the information down, puts it down. It's only, it's only as good as the tool is, as the person who's inputting the data. If there's, if there's no data it doesn't help me...The more information the better, and it's better for the client because I don't have to ask those questions over, and over, and over again because, they get um, uh, things get very convoluted in the sense of they have so many different people calling them. CCAC, VON, all the different providers, right? – Community Care Provider

Both community care and primary care providers discussed that information from community care also needed to be communicated back to primary care, and this was not currently done. The primary care providers had made the referral and wanted to know what had happened to the patient as a result. Community care providers recognized this was an area that needed to be improved.

The researchers have had a conversation with Caredove to make modifications to the referral form. Caredove is adding a place for the AUA Score and reason for referral. This will help pass on information and minimize duplication of assessment. – Memo (December, 2015)

This process is having broader impact on the system outside of primary care, and as a result system-level issues need to be addressed.

6.4.3 Quantitative Results

CIHI Provider Survey Results

The CIHI provider survey was administered at the beginning of the study for baseline data collection. After a period of eight months, the CIHI provider survey was again completed by primary care providers at each study site. In total, 20 health care providers completed the survey. The surveys were completed anonymously so the pre-post results are unpaired.

Note that the first two questions in the chart were posed to physicians only, regarding the referral to specialists (reason for low response number).

Rural Study Site

The following table, Table 6.11, displays the pre and post results of the survey with respect to the questions that were anticipated to show change (indicated in the methods section). Overall there are no statistically significant differences in the data listed below; this would be unlikely given the small sample size. The question related to coordinating care in the community for older complex patients; was anticipated to show change due to the screening and referral process. Although the results show a slight change in the right direction, the results are not significant. In general, the team reported functioning well in the pre-test and that sustained through the study.

Table 6.11. Rural Site Survey Results

Site	Survey Question	Pre Post	N	Mean	Std. Deviation	T	df	P Value	Mean Difference																																																																																																																
1.0 Rural	How fast are referral appointments given?	1.0	4	2.250	1.2583	-.448	5	.673	.4167																																																																																																																
		2.0	3	2.667	1.1547					How fast is referral result information returned?	1.0	4	2.250	.5000	-.205	5	.846	.0833	2.0	3	2.333	.5774	How satisfied with team members communicating about a patient?	1.0	11	4.091	.5394	.139	4.538	.895	.0909	2.0	5	4.000	1.4142	How satisfied with level of understanding other have of my scope of practice?	1.0	11	4.091	1.0445	.145	14	.887	.0909	2.0	5	4.000	1.4142	How satisfied with level of understanding of my role with the team?	1.0	11	4.364	.6742	-.684	14	.505	.2364	2.0	5	4.600	.5477	How satisfied with level of understand of the role of others on the team?	1.0	11	4.636	.5045	1.655	14	.120	.4364	2.0	5	4.200	.4472	How satisfied with the frequency we meet as a team?	1.0	11	4.000	1.1832	1.162	14	.265	.8000	2.0	5	3.200	1.4832	How satisfied with the collaboration across team members for setting goals and plans for patients?	1.0	11	4.182	.7508	.751	14	.465	.3818	2.0	5	3.800	1.3038	To what extent are you able to coordinate services in the community for complex patients?	1.0	11	3.000	.4472	-1.551	14	.143	.4000	2.0	5	3.400	.5477	How satisfied are you with the amount of time available to spend per patient?	1.0	11	4.273	.7862	-.325	14	.750
	How fast is referral result information returned?	1.0	4	2.250	.5000	-.205	5	.846	.0833																																																																																																																
		2.0	3	2.333	.5774					How satisfied with team members communicating about a patient?	1.0	11	4.091	.5394	.139	4.538	.895	.0909	2.0	5	4.000	1.4142	How satisfied with level of understanding other have of my scope of practice?	1.0	11	4.091	1.0445	.145	14	.887	.0909	2.0	5	4.000	1.4142	How satisfied with level of understanding of my role with the team?	1.0	11	4.364	.6742	-.684	14	.505	.2364	2.0	5	4.600	.5477	How satisfied with level of understand of the role of others on the team?	1.0	11	4.636	.5045	1.655	14	.120	.4364	2.0	5	4.200	.4472	How satisfied with the frequency we meet as a team?	1.0	11	4.000	1.1832	1.162	14	.265	.8000	2.0	5	3.200	1.4832	How satisfied with the collaboration across team members for setting goals and plans for patients?	1.0	11	4.182	.7508	.751	14	.465	.3818	2.0	5	3.800	1.3038	To what extent are you able to coordinate services in the community for complex patients?	1.0	11	3.000	.4472	-1.551	14	.143	.4000	2.0	5	3.400	.5477	How satisfied are you with the amount of time available to spend per patient?	1.0	11	4.273	.7862	-.325	14	.750	.1273	2.0	5	4.400	.5477								
	How satisfied with team members communicating about a patient?	1.0	11	4.091	.5394	.139	4.538	.895	.0909																																																																																																																
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Urban Study Site

The following table, Table 6.12, displays the pre and post results of the survey with respect to the questions listed above that were anticipated to show change. For the most part, there are no statistically significant differences in the data listed below. However, the question related to coordinating care in the community for older complex patients did show a statistically significant improvement ($p=0.037$). Similar to the rural site, the team reported functioning well in the pre-test for most of these indicators, and this was sustained through the study.

Table 6.12. Urban Site Survey Results

Site	Survey Question	Pre Post	N	Mean	Std. Deviation	t	df	P Value	Mean Difference																																																																																																																
2.0 Urban	How fast are specialist referral appointments given?	1.0	2	2.500	.7071	.759	11	.464	.4091																																																																																																																
		2.0	11	2.091	.7006					How fast is referral result information returned?	1.0	2	2.000	.0000	.000	12	1.000	.0000	2.0	12	2.000	.6030	How satisfied with team members communicating about a patient?	1.0	13	4.385	.6504	.110	28	.913	.0317	2.0	17	4.353	.8618	How satisfied with level of understanding other have of my scope of practice?	1.0	13	4.154	.6887	-1.562	28	.130	-.3756	2.0	17	4.529	.6243	How satisfied with level of understanding of my role with the team?	1.0	13	4.462	.5189	-1.512	28	.142	-.3032	2.0	17	4.765	.5623	How satisfied with level of understand of the role of others on the team?	1.0	13	4.615	.5064	.129	28	.899	.0271	2.0	17	4.588	.6183	How satisfied with the frequency we meet as a team?	1.0	13	3.846	.8987	-.420	28	.678	-.1538	2.0	17	4.000	1.0607	How satisfied with the collaboration across team members for setting goals and plans for patients?	1.0	13	4.308	.6304	-.183	28	.856	-.0452	2.0	17	4.353	.7019	To what extent are you able to coordinate services in the community for complex patients?	1.0	12	2.083	.5149	-2.198	26.44	.037	-.5637	2.0	17	2.647	.8618	How satisfied are you with the amount of time available to spend per patient?	1.0	13	3.846	.6887	.221	25.34	.827
	How fast is referral result information returned?	1.0	2	2.000	.0000	.000	12	1.000	.0000																																																																																																																
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It is important to make note of the last question, asking providers to rate their satisfaction on the time they have available to spend with each patient. The results from both sites indicate that prior to the intervention, providers were reasonably satisfied with the amount of time they could spend with each patient. While the qualitative results indicated that some providers had

concerns about not having enough time to discuss possible service referrals with their patients, the survey data indicate that following the intervention the providers were still generally satisfied with the time they spent with each patient.

While a larger sample may have found more statistically significant pre-post differences, the above results suggest that most indicators remained stable throughout the study. This is also indicates that the care coordination process did not have any negative effects on the team functioning and satisfaction.

6.5 Discussion

This study further evaluated the use of a screening tool (the AUA) and an online referral process (Caredove) in two primary care settings in Southern Ontario. Key results emerged through data from the screening tools, referral tracking, a provider survey, and individual interviews with patients, caregivers and providers. Data analysis yielded information about the number of older adults screened in primary care, the types of referrals that were made as a result, and five key themes that allows for better understanding of experience. These results provide evidence that a process of care coordination involving a screening and referral mechanism are feasible and acceptable in a primary care setting. Some challenges and broader system issues were identified for future areas of focus.

In total, 512 older adults were screened across two primary care settings. The majority of individuals scored as low risk (70%); 20% screened as moderate risk and 5% screened as high risk. This outcome is consistent with the commonly used ‘Kaiser Triangle’ which illustrates different levels of chronic care, Figure 6.7 (Singh, 2005; NHS and University of Birmingham

Report). For individuals at the bottom of the triangle, self-management is appropriate, for highly complex patients, more intensive case management is important. This was a similar process to the one implemented for this study, as depicted in Figure 6.8.

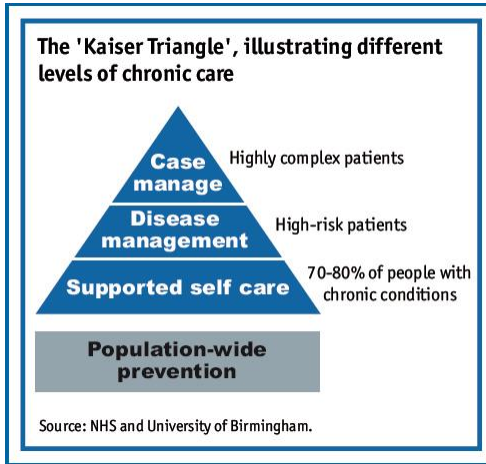


Figure 6.7 Kaiser Triangle

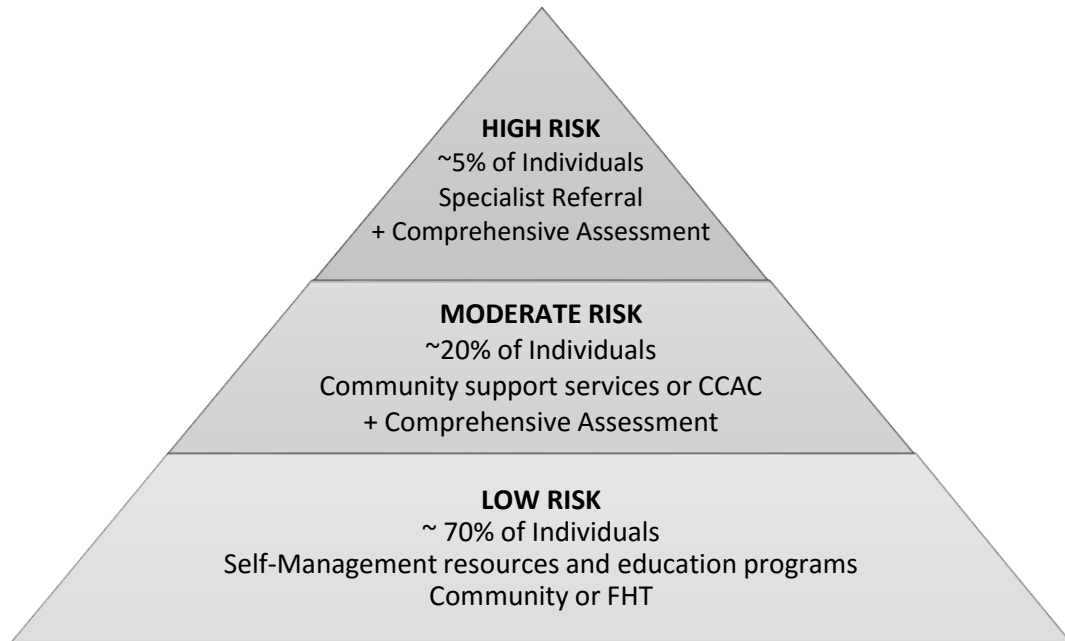


Figure 6.8. Risk Levels and Pathways for Older Adults in Primary Care

The identification of risk alerted the provider to explore the possibility of referring the patient to community and specialist services. As a result, 24 referrals were made through CareDove, and 11 referrals were made internally to primary care services. Providers indicated that the process taught them more about services available in the community and the conversations guided the specific service referral. Although only a small number of referrals were made, these referrals may not have been made without the AUA and CareDove process.

Interviews with patients and caregivers highlighted that they appreciated being asked questions about their life and engaged in decision-making around services. Engagement of patients and their caregivers is important to disease prevention and self-management (Brand et al., 2007). Coulter and colleagues have found that being involved in a more active role in health care can improve patients' quality of care and health outcomes (1999; 2007). Patients also identified that they liked receiving information about services, even if a referral was not made. Increased education also improves patient engagement in decision-making. Patients' skills and knowledge play a role in the level of engagement that they will participate in, patients with more knowledge and education will be empowered and more likely to engage in decision-making (Lavoie-Tremblay et al., 2012; Fraenkel et al., 2007; Powers & Bendall, 2003).

The interviews with health care providers also identified many benefits of the care coordination process, such as building a better relationship with patients, becoming more educated about services in the community, and being able to connect patients to services when appropriate. Providers also discussed how the screening tool led to more open conversations with the patients. Communication between providers and patients supports development of an open, honest, and trusting relationship (Bernabeo & Holmboe, 2013).

The interviews also alluded to some challenges that were experienced by both the patients and the providers including wait times for services, cost of services, and from the provider perspective, the time it took to have the conversation and make a referral.

The pre and post provider survey provided further information about the two study sites. Although the data, for the most part, did not show statistically significant changes, there are a few findings that should be noted. First, coordinating care was identified as an issue in the focus group interviews (Chapter 4), however the rural site did not list it as an issue in the survey. By contrast, the urban site providers' ratings suggested it was an issue at baseline, and there was improvement in the score following the intervention which consisted of a service referral mechanism. Secondly, the pre-survey for both groups indicated that providers were satisfied with the time they had to spend with each patient. Surprisingly, even though time was identified as an issue in multiple provider interviews, there was no difference on the post-survey. It was anticipated that this score could change either way (less satisfied because the process takes time that they do not have; or more satisfied because they are spending more time having a conversation with the patient). A somewhat positive result may have been for providers to report being less satisfied, which would indicate that they valued having conversations with the patients/caregivers and wished they could have more time per patient. This highlights two important points; a) providers may not see conversations or engaging patients as part of their daily role and therefore did not consider this when answering the question (this would indicate the need for a cultural change with care providers) and b) there needs to be an organizational or system shift to allow for more time to work with patients.

Goal Attainment Scaling

Goal Attainment Scaling has been proven to be useful in identifying individualized goals and outcomes for older adults (Stolee, 2010). It was not feasible to include a quality of life measure on all patients in this study, however it was feasible to include a patient-centred approach that gives insight into goals that patients find meaningful. The results of the small GAS study illustrate potential impacts coordinated care could have in primary care settings. The specific goals (education; activities; nutrition) may be helpful for identifying outcomes which could be measured in future studies. As well, these goals could contribute to identifying elements that could be included in a standardized tool (Stolee, 1999; 2010) for use in future primary care studies.

Chronic Care Model

The CCM, was used to guide the implementation and evaluation of the care coordination processes. Figure 6.9 displays the components of the care coordination processes on the CCM framework.

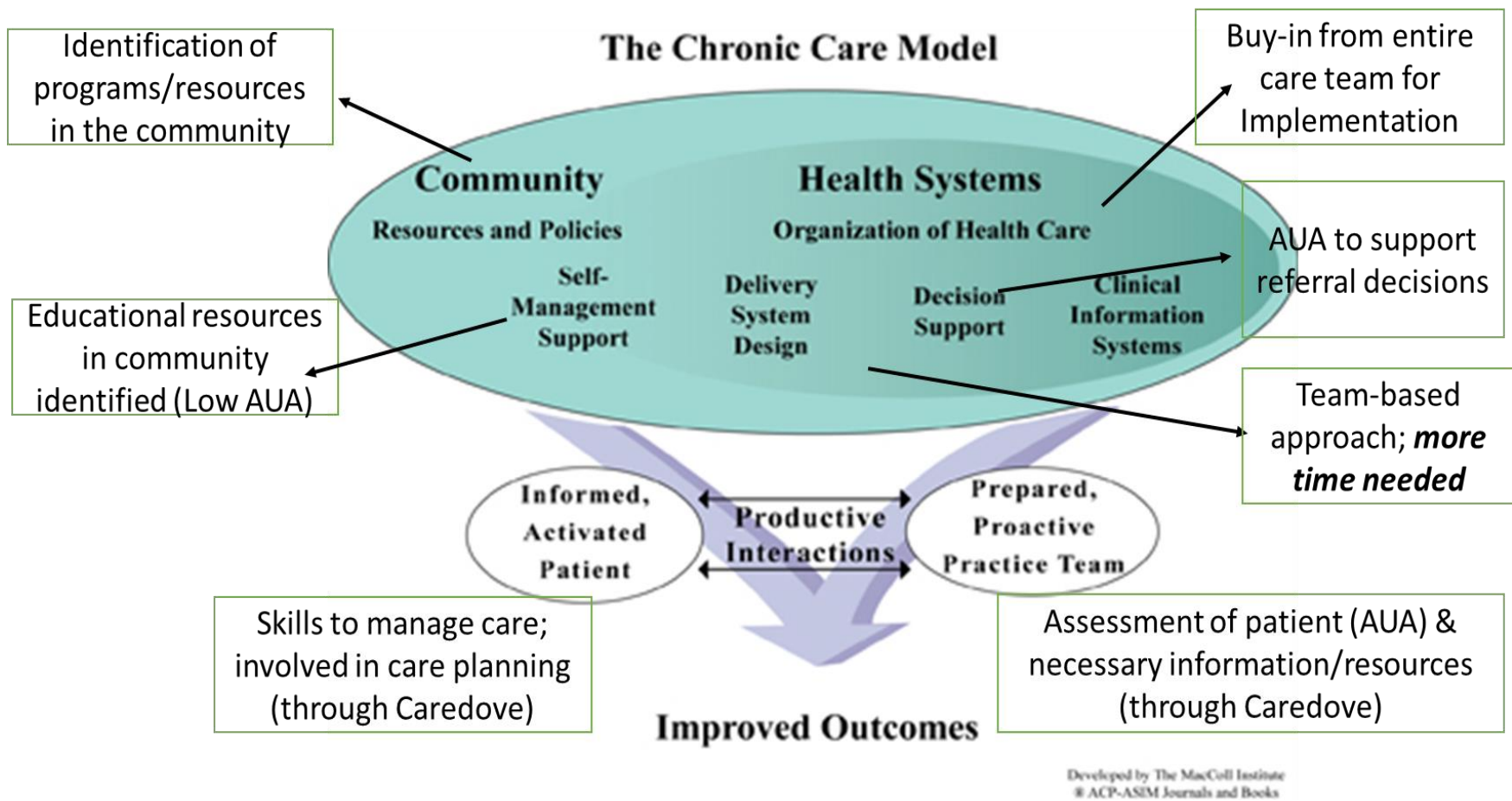


Figure 6.9. Chronic Care Model with Care Coordination Process in Primary Care

The figure above demonstrates the processes that support better care coordination for older adults in primary care settings. Components of the care coordination process addressed many areas of the CCM components including: a) understanding the community resources (identification of services in the community through focus groups and Caredove); b) providing support for self-management (AUA 1 or 2; link patients with education resources in clinic or community); c) having support for the program (needed buy-in from frontline and manager for implementation); d) understanding the delivery of care system (team-based approach but time was still identified as an issues); e) having a proactive team (use of the AUA and Caredove to coordinate services for older adults) and f) informing and engaging patients in decision-making (AUA started conversation and Caredove provided information about services). This provides an understanding of which components of the CCM were addressed with this project. One major component; delivery system change; is out of scope of this project. Although patients and health care providers felt that there were many services available, some had difficulty actually accessing the service for a number of reasons (e.g. cost, wait time, transportation). Furthermore, although health care providers completed the screening and referral process, it is important to note that a team-based model of primary care with salaried physicians still does not allow sufficient time to have the necessary conversations with patients about their care plans and service preferences. A shift in organizational structures and funding models may need to be modified to support fuller implementation.

6.5.1 Qualitative Rigour

Criteria described by Lincoln and Guba (1994) regarding the trustworthiness of the findings (credibility, dependability, confirmability and transferability) were applied. *Credibility* was applied through a member-checking process. During the second interview with patients,

notes from the first interview were discussed to ensure that the participants' realities were accurately represented. Presentations were given to the health care providers and feedback was obtained to ensure their realities were accurately described. *Dependability* was established through triangulation of the data by using multiple data collection methods, sources and informants. These various methods, sources and informants all contributed to the interpretations during data analysis. *Confirmability* was achieved through the use of an audit trail that would allow another researcher or reader to follow the progression of events in the study and understand the logic. The audit trail was on-going and was completed after each event (interview, analysis phase, etc.). Lastly, *transferability* was established through thick descriptions of the findings for each site to allow researchers, planners and practitioners to determine if the results can be generalizable to other settings.

6.5.2 Future Directions

This study resulted in support for the continuation of the care coordination process in primary care, with the identification of barriers that need to be addressed from a larger systems perspective including the issue of time and accessing services.

This model needs to be tested in other primary care settings. Although team-based approaches such as Family Health Teams are increasing, there is evidence here to suggest that this model of care still does not provide sufficient time for providers and patients to have meaningful discussions. Furthermore, there are still many solo-physician clinics in Ontario (~3,000) who may not have a nurse or allied support to assist with this process and therefore it may not be feasible in that context.

Results from this phase of the project also indicate broader system improvements that

need to happen to integrate primary care services with the rest of the health care. These primary care sites are now completing a screening tool and referring patients to services; this information needs to be communicated to the community services to which they are referring to avoid duplication of assessments. This project also pointed to the services that are of interest to older adults who want more support in the community, including gentle exercise programs and housekeeping. Currently, these services have waitlists that will only increase as more older adults undergo risk-screening in primary care settings.

Lastly, providers and patients both discussed the value of having conversations and the relationship building that occurred through the screening and referral process. Current research has focused on understanding how older adults want to be engaged in clinical decision-making and this would provide an avenue to apply those strategies to ensure all patients and caregivers are meaningfully engaged (Stolee et al., 2015; Elliott et al., 2014)

6.5.3 Limitations

There are a few limitations that should be noted for this phase of the study. Again, the study was limited to only two sites within one Canadian province. Both of these sites were Family Health Team models of primary care and therefore the results may not be generalizable to other primary care settings or provinces. Although the specific results may not be generalizable, the overall principles of care coordination, such as the need for a screening tool and referral mechanism, would be relevant for other primary care settings. The development of the specific program and tools would be context specific and should be determined at each site.

A second limitation includes the limited patient and caregiver perspectives, specifically the caregiver and rural patient perspective. The aim was to interview 4-6 individuals in each site

along with 2-3 caregivers but this proved not to be feasible. As a result, it is not possible to say with confidence that saturation was reached, however, the feedback that was provided from all patients and the caregiver was similar and indicated similar benefits of the program and similar barriers.

Lastly, the CIHI survey results showed very little change during the period of data collection. This may have been due to the low sample size, especially for the rural site. The sites seemed well-functioning prior to the implementation of the study and reported functioning well in the follow-up survey. The intervention did not specifically look at providing better interprofessional collaboration or improving team satisfaction and therefore it may not be surprising that the results were not significant. As well, some of the questions addressed on the survey were system-focused, such as relating to receiving information back from specialists. This was out of scope of this project, but an important consideration for future work. Lastly, the survey had one question related to the intervention which was around coordinating care, and there was slight improvements seen by both study sites – this was the indicator which seems most plausibly related to the screening and referral processes introduced in this study. While most indicators showed no change, this may suggest that the interventions did not result in negative impacts on current practice.

6.5.4 Conclusions

This study provides findings that support the use of a screening and referral mechanism to coordinate care for older adults in primary care. This phase of the project resulted in an understanding of the experiences of both the patients and providers through a care coordination process centred in primary care. The results of this study clearly articulate the benefits of the process including improved engagement of older adults and more education for providers and

patients on services in the community. There are some necessary broader system issues that need to be addressed for this process to be successful including more time for patient appointments and better communication between primary and community care.

7.0 SUMMARY AND GENERAL DISCUSSION

The goal of this dissertation was to develop, implement and evaluate a process of care coordination for older adults in primary care. Using a concurrent transformative mixed methods approach within a developmental evaluation framework, this work yielded: a) a greater understanding of the current environment of primary and community care in an urban and a rural setting of Ontario, Canada (chapter 4); b) the identification and iterative development of processes for improved care coordination – including risk screening and an online referral system - for older patients of two primary teams (chapter 5); and c) evaluation of the enhanced process of care coordination in terms of the use and results of the risk screening and referral processes, and patient and provider experiences (chapter 6). Prior to the discussion of the general implications of the overall project, each of the sections from the thesis will be summarized briefly. The chapter will conclude with a discussion of limitations of the overall study and future research opportunities.

7.1 Thesis Summary

Conceptual Frameworks

The Implementation Framework proposed by Chaudoir and colleagues (2012) was chosen to provide guidance during the implementation process. This framework is built on the work of Damschroder and colleagues [2009; Consolidated Framework for Implementation Research (CFIR), which is a widely used framework to support implementation of health services; including support for the implementation of the components of the Chronic Care Model ((Damschroder et al.2009). The Implementation Framework expands on the CFIR with the

inclusion of a focus on a patient level.

The Chronic Care Model (CCM) developed by Wagner and colleagues (1998) provided an organizational framework for understanding practice improvements within a health system and community context. The CCM is widely used for planning and evaluating health system improvements, including improving care in primary care settings (Rothman et al., 2003).

Study Phases

Within the first phase of the project, a series of focus group and individual interviews were conducted to provide greater understanding of the context within which the primary care teams (urban and rural) are operating. Informants were selected to represent a variety of perspectives, including those from primary care and those from community care. Analysis of the focus group and individual interview results generated five key themes. Participants identified the importance of engaging older adults in health care decision-making, but highlighted that this is not currently happening in daily practice. The interviews described uncoordinated care provided to older adults and inadequate information sharing across the system. Participants described the current referral process which included multiple modes of communication (fax, telephone, e-referrals) with services in the community for older adults. Lastly, participants identified some unique challenges with caring for individuals in rural communities. Surveys completed by primary care team members provided additional information on team functioning and the practice environment. The information gathered in this phase pointed to a the need for a referral process that could facilitate links with community services, as well as a screening process that could assist providers in determining which older patients would benefit from which services.

The second phase of the project focused on understanding how to implement screening and referral processes into the primary care sites using a developmental evaluation approach. Developmental evaluation is appropriate for introducing changes into complex systems, when this complexity makes it difficult to pre-determine the specific components of needed interventions or the processes necessary for their implementation. The implementation framework proposed by Chaudoir and colleagues provided an outline of five levels to be considered during the implementation: environment; organization; program; provider; and patients. The interRAI Assessment Urgency Algorithm (AUA) was implemented as a method for risk screening and an online referral system, Caredove, was implemented as a means to refer patients to services in the community based on level of risk. Implementation lessons learned through feedback and ongoing consultations with the study sites included: the importance of buy-in from the whole primary care team, and the need for integrating changes as much as possible into current workflow and practices.

The third phase of the project aimed to evaluate the care coordination (screening and referral) processes, introduced in the second phase, using mixed methods. Interviews, surveys, and assessment forms were collected at each study site. In total, 521 patients were screened using the AUA and a number of referrals were made to community services as a result. Overall, 70% of individuals screened at low-risk; 20% screened at moderate-risk; and 5% screened at high-risk. The interview results illustrated that health care providers saw benefits of this process, including stronger relationships with patients and new knowledge about services in the community. The screening tool was quick, however the conversation that took place after was often time consuming and did not fit into the current workflow of the primary care clinics. Patients appreciated that the providers took time to go over services that are available to them

regardless of whether a referral was made. Both patients and providers valued the processes and hoped that they would be continued in their clinic.

A pre and post provider survey provided information about the two study sites in terms of team functioning, care coordination, and provider satisfaction. The data, for the most part, did not show statistically significant changes, which could be for a number of reasons including the small sample size or the fact that the intervention did not target team function and satisfaction specifically. The survey results did, however, point to the possibility of improved perceived care coordination, which was the primary focus of the project. Overall, the survey indicated that the providers were generally satisfied both before and after the intervention which indicates that although there were no changes in ratings in most areas, implementation of the intervention did not have negative effects on team function.

Understanding the Process of Care Coordination

Developmental evaluation allowed for iterative development of a process of risk-stratified care coordination for older adults in primary care. Through this project, key components of a care coordination process were identified: a) a short, risk screening tool appropriate for use in primary care - the Assessment Urgency Algorithm was adopted for this purpose; b) a streamlined referral system with a service database to connect older adults to services in the community and to educate providers and patients – this was achieved using the online referral tool, Caredove; and c) discussions between providers and patients, opened up by the care coordination process, which supported care planning and helped to build relationships. The processes implemented through this project are consistent with the recommendations of Goodwin and colleagues (2013)

for care coordination in primary care for individuals with chronic conditions, including risk stratification techniques and joint care planning between patients and providers. The findings are also consistent with recent work by McCarthy and colleagues (2015) which indicate several common attributes of successful primary care models, including targeting individuals most likely to benefit from services; comprehensive assessments; care planning; engagement of patients in self-care; and coordinating referrals to community resources. This thesis has identified and tested specific practical tools by which these aims can be achieved.

7.2 Policy Implications

The results of this thesis have a number of policy implications for the provision of primary and community care services to older adults. This project is timely as it aligns with and builds on many current provincial initiatives in Ontario. Firstly, the results from the first phase of the project indicated issues in coordinating care for older adults in primary care, including: lack of information sharing; lack of engagement of patients and caregivers in decision-making; confusion around roles; and lack of knowledge of services in the community for older adults. This thesis provided an opportunity to strengthen the role of primary care within the broader health system, including positioning primary care to identify patients who are in need of services and/or further assessments, and to coordinate care accordingly. This is in accordance with three recent reports; Ontario Seniors Strategy: Living Longer, Living Well: The Living Longer, Living Well (Sinha, 2013); the Patient Care Groups: A new model of population-based primary health care for Ontario Report (Price et al., 2015); and the Patients' First: Ontario's Action Plan for Health Care (MOHLTC, 2015); and with the Ontario Health Links program (MOHLTC, 2015). These documents call for a shift to occur within the Ontario health care system in which

providing coordinated, patient-centred care becomes a greater priority.

The Ontario Seniors Strategy (2013) outlined a number of recommendations including strengthening primary care for older persons and enhancing community and home care services to support aging in place. The report identifies concerns such as inefficient referrals to community organizations and lack of communication between care providers across the system. This thesis project helps to address these concerns, by implementing a tool into primary care that stratifies older adults by level of need, and by facilitating connections with community services. This helps to ensure appropriate access to resources by individuals who would be most likely to benefit. The Seniors Strategy report also urged that CCAC care coordinators be embedded in primary care practices. At one time, both of the study sites had care coordinators, however the rural site coordinator was not integrated into the team and therefore other providers did not know her role, and the urban site had not seen their coordinator for at least 10 months. Although having a community coordinator working closely with a primary care team could be helpful and could support better communication with community services, this thesis has shown that a screening and referral process may be feasible in primary care settings within the current resources. The thesis has also shown however that even with efficient screening and referral processes, the time required for conversations with patients that are prompted by these processes is a challenge for primary care providers within current practice models.

The Ontario Government recognized the need for system change and set out an agenda to shift the delivery of health care. *Health Links* aims to provide coordinated, efficient care to patients with complex needs (the top 5% of health service users) by encouraging collaboration and coordination among providers through the development of personalized care plans. The Health Links initiative identifies those individuals at high risk (through an unstandardized

process) and supports development of appropriate care plans. The roll-out of this project varies across the province in terms of how people are identified as high risk and how care plans are structured. As seen through this thesis project, the implementation of the AUA provides an efficient way to identify high-risk patients, but also allows for identification of individuals at moderate risk who may need more support from community organizations, and those at low-risk, who may benefit from education or supports for self-management. This thesis research thus supports the aims of the Health Links initiative by providing a standardized method for identifying primary care patients at high risk, but also support identification of patients at lower risk for whom interventions and prevention efforts may prove beneficial.

The Patients' First report identifies key objectives for providing better care to Ontarians: a) Access – providing access to the right care; b) Connect – delivering better coordinated and integrated care; c) Inform – provide education and information to make decisions; d) Protect – protect universal health care. This thesis identifies mechanisms to support older adults that align with these provincial objectives. The use of a standardized screening tool helps to ensure older adults are *accessing the right care* including self-management supports, community services, or specialist care. Through this project, primary care providers are now better linked with the rest of the system through the use standardized assessments and referral mechanisms. Although there are still broader system issues to be addressed, this thesis project has started a mechanism for *primary care to be better integrated into the health care system* and to become the central coordinating hub for older patients. The thesis also demonstrates a process where health care providers are having conversations with patients about services in the community, thus building relationships and *educating and informing* patients so that they can make decisions that are best for their situation. The care coordination processes were implemented within current primary

care resources, supporting their sustainability and helping to *protect universal health care*.

7.3. Implications for Models of Primary Care

Functions and characteristics of primary care have been described as; the first point of contact, continuous, comprehensive and coordinated care (Starfield et al., 2005). These functions would suggest primary care has a central position within the health system to support integration of services (Valentijn et al., 2013). The Canadian Medical Association recommends that primary care physicians should assist older adults in navigating the complex health care system and should be responsible for coordinating services (CMA, 2015). However, Tracy and colleagues (2013) found primary care physicians do not have adequate time to manage older adults with complex conditions. Models of interprofessional collaboration, such as a Family Health Team, have been introduced in many primary care settings (Tracy et al., 2013) in efforts to address these issues.

This thesis project aimed to implement a process that would improve coordinated care in team-based primary care settings – Family Health Teams. Yet, even in Family Health Teams, which were designed to facilitate more coordinated and integrated care, having meaningful conversations with a patient about service options was challenging during short appointment times. Although providers generally thought the process was beneficial and empowering, and they would continue the process, they did find the conversations and referral process time consuming. This raises the question of whether this process would be feasible in other models of care such as solo-physician practices, which do not have allied health professional assistance. Some evidence suggests that coordinators (e.g., from CCACs) should be embedded in primary care to take on the coordination role (Sinha, 2013), however it may be more feasible to look at

organizational change within the primary care practice, such as expanding the role of existing primary care providers to assist with coordinating care. For example, the role of nurses in primary care has sometimes been limited to medication reconciliation and health documentation (Smolowitz et al., 2015). Research has indicated that nurses' scope of practice has been limited by physician mistrust and unclear roles (Oelke et al., 2014). This thesis project supports recent research which has indicated that nurses and other primary care staff could have a larger, care coordinating role (Parker & Fuller, 2016). In this project, nurses and medical office assistants were completing the screening and referral process and reported feeling empowered to help patients. Parker and Fuller (2016) found that increasing the role of nurses frees up physician time and care provided to patients is more proactive.

Risk Screening in Primary Care

Research has examined screening tools for risk in other health care sectors, such as the Identification of Seniors at Risk (ISAR) tool, which is an emergency department self-administered, six item screening tool (Dendukuri et al., 2004). Ensuring at-risk patients who arrive at the emergency department have appropriate follow-up and services is important, however this thesis project demonstrated the feasibility of screening for risk in primary care, potentially avoiding a future emergency department visit. Theou and colleagues (2015) state that identifying older adults who are at risk of experiencing adverse health outcomes should begin in general primary care practice, further supporting the results of this thesis.

Practical tools are needed to identify older community-dwelling older adults who are at risk (O'Caoimh et al., 2015). The review by O'Caoimh and colleagues (2015) identified age, activities of daily living (ADLs), caregiver availability and self-rated health to be common

predictors of adverse health outcomes and should be included on screening instruments. This thesis implemented the interRAI Assessment Urgency Algorithm, a short risk-screening tool with the following domains; ADLs, cognition, self-rated health and mood, shortness of breath and unstable conditions (Hirdes et al., 2010). The project indicated that this is an appropriate tool for primary care settings and was acceptable by the health care providers who used the tool.

Coordinating Care in Primary Care

Previous work has identified challenges in coordinating care for older adults with complex conditions, such as multiple providers and multiple care plans (Bodenheimer, 2008; Boyd et al., 2007). Care coordination should take place in primary care, however primary care physicians cannot provide care coordination functions during a 15-minute visit (Bodenheimer, 2008). Bodenheimer and colleagues (2008) suggest a number of ways to improve care coordination practices in primary care including using allied health professionals as support, addressing the lack of system integration and supporting coordination with electronic referral systems. This thesis project aimed to improve care coordination through a process of risk screening and referral. The screening allowed for identification of individuals who would most likely benefit from a referral. This process was completed by nurses and medical office assistants in the primary care settings. The referral process in this project was also facilitated by an online system. Although more work needs to be done to address the issue of “time to have conversations”, the results of this study indicate that primary care can be more fully integrated into the broader health system and play a more important role in screening and coordinating appropriate care for older adults.

Considerations for Urban and Rural Primary Care Sites

The results of this study also point to important considerations for future work in urban and rural primary care contexts. The study results from the rural site indicated a higher proportion of moderate and high risk individuals. The nurses also felt it was appropriate to screen some individuals under 70 years of age. This is supported by data from Statistics Canada (2008) that states rural communities have higher proportions of older adults (65 years of age and older) and the rural population is aging faster than urban populations. In terms of referring older adults to services, data from the rural site indicated issues with finding services that were free for the patient, or did not require transportation. There are many barriers to accessing health services in rural communities, including transportation difficulties, social isolation and financial constraints (Goins et al., 2005). As a result of this study, Caredove is going to make a specific search option available to search for services that are free of charge.

In initial focus group interviews with rural providers, coordinating care was an issue, but providers acknowledged the benefit of working in a small community where “everybody knows everyone” and providers could pick up the phone and call a colleague. However, in both rural and urban contexts, providers saw the value in having a system that assisted in the coordination process and provided a database of the services offered in the region.

In both sites, time to have meaningful conversations with patients was identified as a factor, indicating a need for change to the structure and organization and/or payment mechanisms of Family Health Teams.

7.4 Research Implications

Primary care reform is still a relatively new and under-researched area (Levesque et al., 2015). For the health system to meet the growing demands of an aging population, research will be necessary to provide evidence for health system transformation. This thesis demonstrated a number of areas that contribute to current research and knowledge, including: an evaluation approach for complex health systems; a reasonable screening process for older adults in primary care; and a mechanism for referring patients to services in the community through conversation and joint decision-making. These findings help to inform an integrated model of care that engages primary care providers, patients and families as partners in care coordination across the system. This work also demonstrated the appropriateness of the Chronic Care Model as a guide to improving care in primary care settings. The initial findings from phase 1 (Chapter 4) were mapped onto the framework and thus identified areas that needed to be addressed such as; a common decision-support system; improving knowledge on community resources; better informing patients; and better care coordination. A process for screening and referrals was successfully implemented in two primary care teams, and as a result, addressed many of the issues identified in phase 1. Future work needs to focus on the implications for the broader health system, including better service integration across the entire health system.

This thesis highlights the appropriateness of a developmental evaluation approach for implementing and evaluating changes within a complex health care system. The approach allowed the researcher to become part of the team in an ongoing process of continuous modifications. This collaboration yielded a process of care coordination based on both research and input from individuals who use the program every day. Additionally, an ethnographic approach within a developmental evaluation process was appropriate because of the sustained

engagement between the researcher and the study sites. Ethnography calls for the researcher to be immersed in the study site for an extended period of time. Figure 7.1 below displays the time period for which this research was completed, demonstrating the long process of engagement.

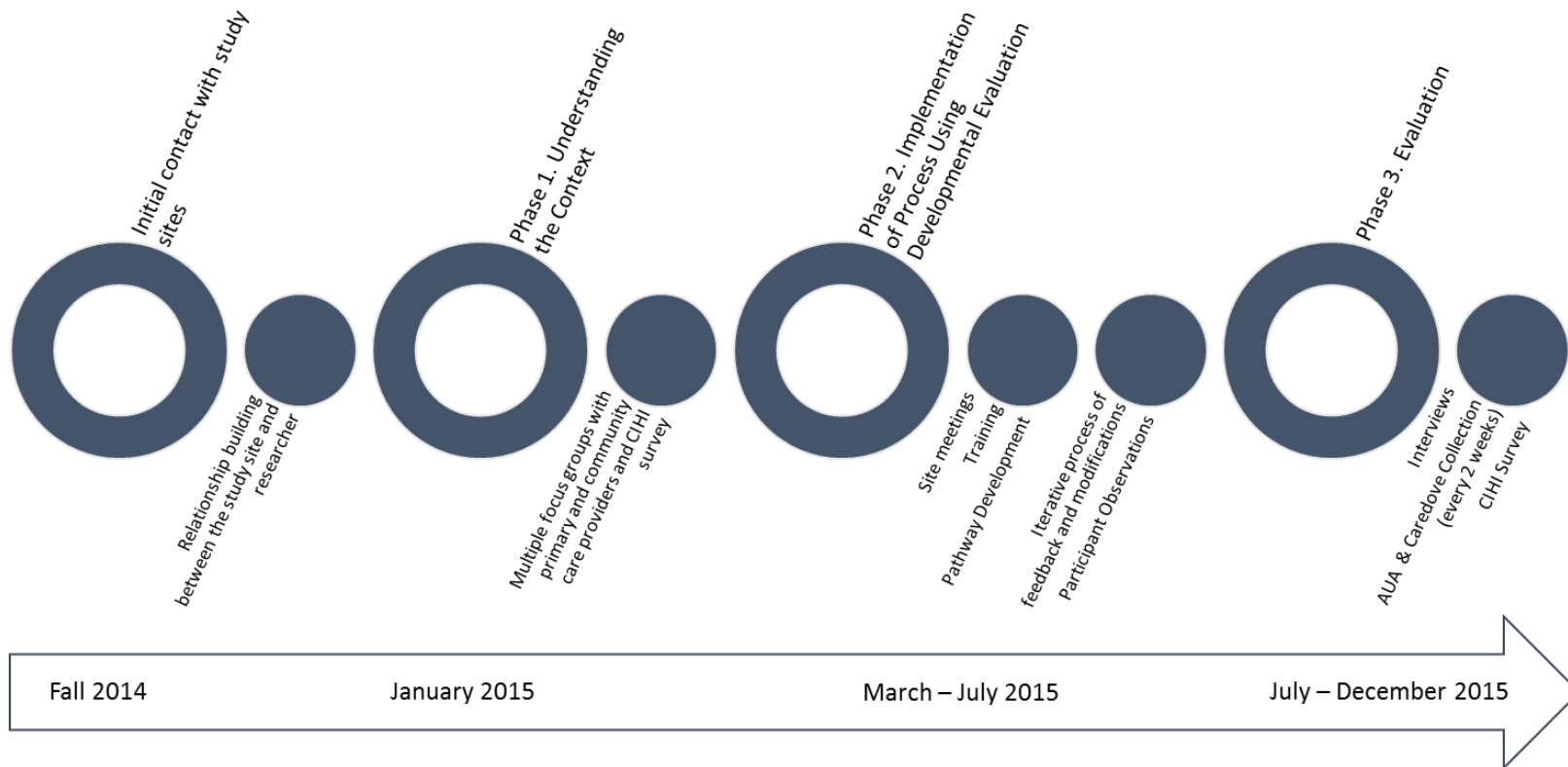


Figure 7.1. Timeline and Integration into the Study Sites⁷

⁷ Larger circles identify the study phases, small circles describe specific actions and the arrow indicates the time frame

Application of the implementation framework proposed by Chaudoir and colleagues provided guidance on needed elements of successful implementation of changes in care processes in team-based primary care settings. At the outset, the system needs to be considered in terms of funding availability and how the primary care team fits within the larger health system. Mechanisms should be identified to link and coordinate care efforts between primary care and the rest of the system. Organizational issues need to be considered including the management approach and payment process for physicians. Buy-in is needed from the entire primary care team before changes will be effective. Depending on the payment schedule, providers may not be willing to try a new process that takes more time in the current funding model. Next, the program itself should be considered. The use of a flexible method such as developmental evaluation is helpful to quickly identify issues and make modifications to improve acceptance of the program. The providers play an important role, therefore having providers to participate in the implementation process, to ensure the program fits within their scope of practice, allows for better adherence to the program. Finally, it is important to consider the needs of, and impact on, the patient. Patient representatives on the implementation team would be valuable to provide input and feedback.

7.5 Limitations

This thesis project has a number of limitations. First, the thesis project took place in two team-based primary care teams (Family Health Teams) in Southern Ontario limiting the generalizability of results to other primary care models in other jurisdictions. While evaluation in additional sites was not feasible for this project, undertaking the research in both an urban and a rural setting provides some information and insights about implementation in different contexts

and constellations of community resources and services.

Another important limitation is that only a small number patients were interviewed (n=6). Unfortunately it was difficult to recruit patients within the study time frame. The patients who were involved in the study however represented different age groups, genders, geographical locations (urban/rural), and AUA risk score. Therefore, although there was limited participation, the data that were collected provided valuable information from a range of individuals.

The survey that was used in this study produced results that were largely stable between the pre-implementation and post-implementation phases. Although most results were not statistically significant, there were some interesting findings noted in a few of the relevant domains. It is important to recognize that this specific project was not targeting interprofessional collaboration and team functioning, thus these would not have been expected to change. As well, the sample size was small, particularly at the rural site.

Lastly, this thesis project was conducted in team-based primary care settings with allied health professionals who supported the screening and referral process. Issues were experienced by providers who needed longer appointment times to discuss referral options and care plans with patients and caregivers. As such, this process may not be feasible in solo-practitioner clinics where the physician would not have team support to complete the process. The needed elements of care coordination are still important, but the processes to achieve these would need to be modified. For example, the screening could take place at one appointment and if the patient screens as being at moderate or high risk, a second appointment could be scheduled to discuss service referrals. interRAI is developing a self-administered screening tool that patients could complete in the waiting room and Caredove is developing a self-referral option for some of the community services. However, there could be issues with literacy levels and patient motivation. These options could help with feasibility in solo-practitioner clinics and other settings with

limited resources, and should be tested in future research.

7.6 Future Research Directions

There are a number of important considerations for future research. A subsequent program of research should focus on better communication between primary care and community care. This thesis project implemented interRAI assessments into primary care and provided primary care providers with education on the assessments used in many parts of the Ontario health care system. Primary care teams are now completing the screening process and making referrals, however information related to the screening results would be helpful for community care providers. As well, primary care providers want feedback from community providers on whether their patient is either receiving services or wait-listed. A similar process to the one used in this project, developmental evaluation, could be used to understand the information each health sector needs to know about their patients, and the best way to document and communicate that information given the multiple EMR systems used in Ontario and elsewhere.

Secondly, this thesis demonstrated the feasibility of a quick screening tool and referral mechanism in team-based primary care settings. In subsequent research projects, an experimental design could be used to test the impact of the AUA and referral processes on patient and system outcomes. A longer period of follow-up would allow measurement of differences in outcomes and health and community service utilization.

Lastly, this thesis project was conducted in Family Health Team models of primary care. Future research could examine implementation and evaluation of screening tools and referral processes such as the AUA and Caredove in other models of primary care, including Community Health Centres and Nurse Practitioner-Led clinics. Methods to achieve aims of improved care

coordination in non-team-based primary care settings should be developed and tested.

7.7 Conclusions

This dissertation has examined the development and implementation of a process of care coordination for older patients in primary care. This work has developed an understanding of the current state of primary care in two locations, one rural and one urban; a process for implementing programs into complex health systems; and a better understanding of patient, provider and caregiver experiences in primary care. The results of this work illustrate that developmental evaluation is a promising method for evaluating complex health systems. They also demonstrate that processes of screening and of coordinated referral are feasible in team-based primary care settings. Wider implementation of these processes has the potential for significant benefits for older patients and for health care system integration. Future research is necessary to identify ways that these processes could be refined and improved, and to test their longer-term sustainability and effectiveness.

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APPENDICES

Appendix A: Chronic Care Model – Image Permission

Appendix B: Community Focus Group Interview

Appendix C: Health Care Provider Focus Group

Appendix D: SHARP Focus Group Interview

Appendix E: Patient Individual Interview Guide

Appendix F: Family Caregiver Individual Interview Guide

Appendix G: Health Care Provider Individual Interview Guide

Appendix H: Letter of Information and Consent Form for Health Care Provider

Appendix I. Study Recruitment Script

Appendix J: Information Letter and Consent for Patient

Appendix K. Information Letter and Consent for Caregiver

Appendix L: Observation Guide

Appendix M: Research Ethics Board - Approval

Appendix N: Assessment Urgency Algorithm Decision Tree

Appendix A: Chronic Care Model – Image Permission

Jacobi Elliott

From: Helen Canavan <hcanavan@mail.acponline.org>
Sent: January 26, 2016 4:00 PM
To: Jacobi Elliott
Subject: Re: Image Use

Jacobi,

Thank you for contacting us with your permission request.

You have permission to use the Chronic Care Model for use in your thesis/dissertation at no cost.

Please contact me with any questions,

Helen

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>>> Jacobi Elliott <jacobi.elliott@uwaterloo.ca> 1/25/2016 3:03 PM >>>

Hi there,

I am looking to obtain copyright permission to use an image in the Effective Clinical Practice: ECP. The image is *The Chronic Care Model (1998)*. I emailed the MacColl Center and they directed me to the Copyright Clearance Centre to obtain a \$0 copyright permission for use in a thesis/dissertation. When I select Thesis, the cost shows \$378. How can I obtain the \$0 permission?

Many thanks,
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--

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Appendix B: Community Focus Group Interview

1. Could you please tell me about your role/organization?
 - How long have you been working in your role?

2. How do you receive referrals for services? How are people connected to your services?
 - What are some barriers or facilitators to assisting older patients?

3. What sort of services does your organization offer for older adults?

4. How does information about the patient get communicated back to the clinic/other health care providers?

5. Do you think patients/caregivers are engaged in decisions around which resources would be best for them?
 - How?

6. Please describe the type of (older adult) patient your organization would typically service?

7. Are there services that are accessed more frequently than others? Please explain. Which resources seem to be most helpful? Least helpful? Why?

8. The AUA that is being implemented into primary care stratifies older adults into levels according to risk. Are there certain services that would be more suited for people at low risk (independent individuals) vs. medium risk vs. high risk (more dependent individuals)?

9. It seems that there is a major role in coordinating care for people – do you think there should be a care coordination/system navigation role in primary care for older adults?
 - Describe what this role would look like? How could it benefit your organization?
 - New role? Part of someone's role?

10. We would like to use an “activity tracking form” to track the patient's journey through the health system (what resources were they referred to, did they go, what is their care plan, etc.) – what are your thoughts?
 - Is there any information you would like included on the form so that if you received it, the information would be readily available on the form?

Appendix C: Health Care Provider Focus Group

1. Could you please tell me about your role/organization?
 - How long have you been working in your role?

2. Do you currently use any standardized assessments on your older patients?

3. We would like to get your thoughts and suggestions about how we can best implement the Assessment Urgency Algorithm into your clinic.
 - Ask about each of the intervention components – You have just learned about the AUA... What do you think the pathway should look like for someone at :
 - Low Risk
 - Medium Risk
 - High Risk

4. What are the foreseeable barriers to implementing the intervention components? How can we overcome these? What resources or supports do you need?

5. Are you currently referring older patients to community services?
 - ***If not-* Are you aware of any community services that could benefit older adults at low/medium/high risk levels?
 - ***If yes-* Are you aware of the adherence to community services referrals?

6. How do you current refer older patients to community services?
 - **Do you currently collaborate/ communicate with community services/ agencies that provide services to your older patients?*

7. Can you tell me about how older persons and their families are engaged in setting goals or making decisions about their care?

Appendix D: SHARP Focus Group Interview

Introduction to explain research study

Let's talk about services in your community.

1. If you have been referred to services in the past, which services and supports did you find to be most helpful? (health care professionals (which ones?), family, friends, community agencies, FHT, website, etc.)
2. How did you find out about those services and supports?
3. Did you get them on a timely basis? Some more than others?
 - a. *And if not specifically addressed: Were you able to get access to your family doctor on a timely basis? What about specialists?*
4. What services and supports were the least helpful?
5. What services and supports do you wish you had had access to?
6. What do you think is the role of your family doctor in connecting you to supports and services?

For any of the care pathways, would you recommend a techniques that would help you access services? –

1. Do you think your family or friends knew how to help you? Why or why not?
2. Would you appreciate working with someone who can help you navigate the system?
3. What do you think about a system navigator role? What would this look like?
4. Describe what you think this might look like?
5. What would you want their role to be?
6. Who would do this?

In terms of the screening assessment?

1. How does this sound to you?
2. If your doctor completed the screening tool at your next appointment – would you be interested in the care pathways? Would you like to take part in the decision making around what services you will be referred to??

Appendix E: Patient Individual Interview Guide

Initial/baseline:

- General background information:
 - Year of birth, male/female, etc.
 - Can you tell me about your current health status?
 - What is your current level of activity?
 - Where are you currently living?
 - ***Probe for living alone, care giver, etc*
- Recently you were asked to check in with the clinic, and the nurse asked you a few questions about your health and how you are getting along. Can you walk me through what happened when you came in for this visit?
 - Did you have opportunity to ask any questions? Did you have an opportunity to raise any other concerns or needs that you may have had?
- Were you given any advice or suggestions, or a referral to another physician?
 - ***Probe for specific intervention components: referral map, system navigator, specialist referral*
- How involved do you feel you were in those discussions and any decisions that were made related to your care? *Explain*
- Did you receive any information on how you might better manage your health concerns? *Explain*
- Do you feel confident that you understand how to follow the recommendations and information given to you?
- Do you see yourself following the suggestions and recommendations you received?
- (If referred to any community resources) Can you walk me through the process of accessing the community services you were referred to?
- Do you feel that all of your questions were answered?
- What are your current health care goals?
 - *Better diet, more exercise, etc.*
- Is there anything else you want to share about your experiences in the FHT today?

Follow up (3 months):

- Have you been to the hospital in the last 3 months?
- At your last appointment at the clinic, were you informed about any community services to assist you with your health?
 - Have you accessed any of these community services? Why/ not?
 - Have you noticed any changes in your health since joining these?
- Previously you mentioned ____ as a goal you had set for yourself, how is that going? Have any of your goals changed?
- Would things be different if you worked with someone to navigate this system? How? Explain?

Appendix F: Family Caregiver Individual Interview Guide

Initial/baseline:

- General background information:
 - Year of birth, male/female, etc.
 - Can you tell me about your current health status?
 - What is your current level of activity?
 - What your relationship to the patient?
 - How long have you been involved in caring for your friend/relative?
 - How have you been involved?
- Can you walk me through what happened when your friend/relative came into the (name) FHT today?
- Did you receive any information about your friend/relatives' care?
- Was your friend/relative encouraged to access any community services?
 - Were you and your friend/ relative given the information you needed to do this?
- In thinking about your involvement with health care decision, did you feel engaged in the decision-making process?

Follow up (3 months):

- Has your friend/relative been to the hospital in the last 3 months?
- At your last appointment at the clinic, were you informed about any community services to assist you with your friend/relatives' health?
 - Have they accessed any of these community services? Why/ not?
 - ****If yes-** Have you noticed any changes in your friend/relatives' health since joining these?

Appendix G: Health Care Provider Individual Interview Guide

- Please walk me through the process of using the assessment and coordinating care for older adults?
- Does the screening and referral process make a difference in the practices at this clinic?
 - Are there any barriers? Facilitators?
 - What can make this process better?
- How are you engaging patients and caregivers in health care planning and decision making?
- How are you communicating care plans with patients? Any ideas for improvement?
- How are you communicating with community care organizations? Do you receive follow up information? *How?*
- Do you feel less of your patients are showing up in the emergency department?
- Do you feel this process is sustainable?
- What do you need to make this sustainable?
 - ***Probe for resources – manpower, funding, materials etc.*
- Are you aware of other team members who can assist with care planning?
- Is there anything else I should know about this process? Final comments?

Appendix H: Letter of Information and Consent Form for Health Care Providers

Date:

Study Name: Risk Assessment and Care Coordination for Older Persons in Primary Care

Principal Investigator: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 x35879

Student Investigator: Jacobi Elliott, PhD Student; j7elliott@uwaterloo.ca; 519-888-4567 x38982

A. WHAT IS THE PURPOSE OF THIS STUDY?

Seniors are among the largest growing segment of population in Canada, as well as being the greatest users of the healthcare system. Therefore, it is essential to understand the challenges related to health system integration and also, the continuity of care for seniors. The key lies in identifying strengths and gaps in developing an integrated system of care for frail seniors. The aim of this research program is to develop and monitor an integrated primary health care (PHC)-centred approach to improve the assessment and management of older persons with chronic disease (CD). We will learn about care coordination including; referral and care processes, patient and caregiver experiences and engagement in shared decision-making about care, and provider satisfaction.

B. WHO CAN PARTICIPATE?

We are looking for senior patients who are 65 years of age who attend various primary care locations. To get a full picture of what the patient is going through, we would like to speak to the patient's caregiver as well as health care providers and community stakeholders with whom patients may have interactions with.

C. WHAT WILL I BE ASKED TO DO?

Interviews: We are asking health care providers and community stakeholders to participate in interviews to understand current care and referral processes and experiences. The interview will take approximately an hour to complete. Before beginning the interview, you will be asked to confirm that you agree to participate. The interviews will be audio-recorded and we will make use of quotations with your permission. An identifying information will be removed.

Questionnaire (for Health Care Providers only): If you agree to participate, you will also receive a questionnaire that you can fill out on your own time. The questionnaire, *CIHI Provider Survey*, focuses on provider demographics, structure of the organization, and interprofessional collaboration with other health care providers at various primary care locations. The questionnaire will take approximately 15 minutes to complete. The Executive Director of the primary care team will complete the CIHI Organizational Attributes which provides information about the organization. This will take approximately 25 minutes to complete.

Observations (for Health Care Providers only): A member of the research team will also be observing interactions between you and your patients and their family/caregivers and you and other care providers. These may be interactions that occur in the common areas such as hallways and waiting room of the clinic, or with permission from the patient in meeting rooms during a family meeting to discuss self-care. You or the patient may ask the observer to leave or not to be present during any conversations or discussions.

Focus Group: Participants will be asked some questions relating to understanding care and referral processes. Focus groups will take place at the beginning of the study and after 6 months, with other health care professional or community stakeholders and will last approximately 1.5 hours. The focus groups will be audio-recorded and we will make use of quotations with your permission. An identifying information will be removed. This information will help to improve the health care system for older adults.

D. WHERE WILL THE STUDY TAKE PLACE AND WHEN?

The study will take between 3-6 months at various primary care centres, or until we consent approximately 30 patients and caregivers. Your participation will only require you to participate in an interview, questionnaire and focus group

E. CAN I CHANGE MY MIND ABOUT PARTICIPATING IN THE STUDY?

You may withdraw from the study at any time. Withdrawal from the study will not affect your position at the health clinic. If you wish to withdraw,, you can let the interviewer know any time during the interview, or you can call Jacobi at 519-888-4567 x38982.

F. RISKS AND BENEFITS

There are no known or anticipated risks associated with your participation. You will not receive remuneration for participation in the study.

G. CONFIDENTIALITY AND DATA SECURITY

The information you provide will be kept confidential and identified by number only. Your name will not appear in any report or publication resulting from this study. Any quotations used in reports from your interview will be referenced as anonymous.

You have the right to ask the researchers about the data being collected about you for the study and about the purpose of these data. You also have the right to ask the researchers to let you see your personal information and make any necessary corrections to it.

Data collected will be kept securely stored in a locked office for a period of 5 years, and then confidentially destroyed. The answers to the interview will be stored in a locked file cabinet, in a locked office, at the University of Waterloo for a period of 5 years. After 5 years, any written notes from the interview will be confidentially shredded and electronic files will be erased after 5 years. Only members of the research team who have signed a confidentiality agreement regarding information collected during the study, will have access to the study data.

H. QUESTIONS

If at any time you have questions about the proposed research, please contact the Principal Investigator: Paul Stolee, PhD, School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, 519-888-4567 ext.35879, stolee@uwaterloo.ca or **Student Investigator:** Jacobi Elliott, PhD Candidate, School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, 519-888-4567 ext. 38982

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. The final decision about participation is yours. Should you have any questions or concerns arising from your participation in this study, please contact Dr. Maureen Nummelin, Chief Ethics Officer, at 1-519-888-4567, Ext. 36005 or Maureen.nummelin@uwaterloo.ca.

I. CONSENT TO PARTICIPATE

I have read the information letter about the study being conducted. I know that the study is being conducted by *Jacobi Elliott (PhD Candidate)* from the School of Public Health and Health Systems at the University of Waterloo, under the supervision of Dr. Paul Stolee. A portion of the information collected will be used for Jacobi's PhD dissertation.

I was informed that you would like my help to better understand how older adults are engaged in care at the clinic and to improve experiences of myself and others. I was informed that my participation in this study involves an interview, completion of a questionnaire, participation in a focus group, and involvement in observations (optional). I understand that this study will start next week and will be recorded.

I have made a decision to participate in the research study based on the information I have received in the discussion with the researcher(s) from the University of Waterloo. I have had the opportunity to ask questions and receive any additional details I wanted about the study. I also understand that I may decline answering any of the questions, if I so choose and I am free to withdraw from the study at any time by telling the researchers that I no longer wish to continue.

All information that I provide will be held in confidence and I will not be identified in any reports or publications resulting from this research. I was informed that any quotations taken from my interview(s) will be referenced as anonymous in any publications of this research.

I was informed that as part of this study the research team will be discussing my experiences, and referral and care processes. I was informed that as part of this study, the research team will be observing interactions between me and my patients (who have consented) and my colleagues.

Please note, by signing this consent form you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

(Check the box or boxes indicating the parts of the study you agree to participate in)

- I agree to participate in this study**
- I give consent for quotations from my interview and focus group to be used in reports where they will be referenced as anonymous.**
- I agree to be audiotaped during the interview and focus group**
- I agree to be observed**

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

YES, please e-mail me a summary of the results. My e-mail address is:

YES, please mail me a summary of the results. My mailing address is:

NO, I do not wish to receive a summary of results

The research study has been reviewed by and received ethics clearance through a University of Waterloo Research Ethics Committee.

Appendix I. Study Recruitment Script

Risk Assessment and Care Coordination for Older Persons in Primary Care

Contact:

Principal Investigator: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 x35879

Student Investigator: Jacobi Elliott, PhD Student; j7elliott@uwaterloo.ca; 519-888-4567 x38982

Good morning/afternoon,

Currently a University of Waterloo study is being done at this clinic. This study focuses on improving the health care system for older adults and is being conducted as a research project through the Faculty of *Applied Health Sciences* under the supervision of **Dr. Paul Stolee**. Our focus is on understanding the experience at this health care clinic from the perspective of older adults and their caregivers.

Because you are a patient and caregiver at this clinic, your opinions may be important to this study. Thus, I would appreciate the opportunity to speak with you about this.

Participation in this study is voluntary. If you want to participate you would be asked to take part in two face-to-face interviews with a researcher from the University of Waterloo at the end of your appointment today or at a time convenient for you. Your caregiver/spouse is also invited to participate in the study. Interviews will be audio tape recorded. The researchers would also like to ask your permission to observe the interactions during your visit to the Family Health Team clinic. This may be interactions between you and members of your health care team and your family or family caregivers. These interactions could occur in the common areas of the clinic such as hallways or waiting rooms, but also during family meetings.

There are no known or anticipated risks to your participation in this study. The questions in the interview and survey are quite general (for example, what do you like about your experience at this clinic?). You may decline answering any questions you feel you do not wish to answer. Also, the observation component is optional. All information you provide will be considered confidential and grouped with responses from other participants. Further, you will not be identified by name in any report or publication resulting from this study. If you have any questions about this study, or would like additional information to assist you in reaching a decision about participation, please feel free to contact **Dr. Paul Stolee** at 519-888-4567, Ext. 35879.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee.

Thank you for your assistance with this project.

Appendix J: Information Letter and Consent Letter for Patient

Date:

Study: Risk Assessment and Care Coordination for Older Persons in Primary Care

Principal Investigator: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 x35879

Student Investigator: Jacobi Elliott, PhD Student; j7elliott@uwaterloo.ca; 519-888-4567x38982

A. WHAT IS THE PURPOSE OF THIS STUDY?

Seniors are among the largest growing segment of population in Canada, as well as being the greatest users of the healthcare system. Therefore, it is essential to understand the challenges related to health system integration and also, the continuity of care for seniors. The key lies in identifying strengths and gaps in developing an integrated system of care for frail seniors. The aim of this research program is to develop and monitor an integrated primary health care (PHC)-centred approach to improve the assessment and management of older persons with chronic disease (CD). We will learn about care coordination including; referral and care processes, patient and caregiver experiences and engagement in shared decision-making about care, and provider satisfaction.

B. WHO CAN PARTICIPATE?

We are looking for senior patients, like yourself, who are 65 years of age and older attending primary care centres. To get a full picture of what patients are going through, we would also like to speak to your caregiver/spouse. As part of this study, we are also speaking with members of your health care team

C. WHAT WILL I BE ASKED TO DO?

Interviews: We are asking both patients and caregivers to participate in a face-to-face interview at the end of your appointment today or at a time that is more convenient for you. We would also like to contact you again by telephone for a follow up interview if necessary in 8-10 weeks. The interviews will take approximately 30mins-45mins each to complete. Most of the questions that you will be asked will be about your experiences with the health care system. Before beginning the interviews, you will be asked to confirm that you agree to participate. You will also be asked a few demographic questions (e.g. your age). The interviews will be audio-recorded and we will make use of quotations with your permission. An identifying information will be removed.

Observations: If you agree, a member of the research team would like to observe interactions between you, your family member/caregiver, and your health care providers to learn about, for example, a time when your health care provider talks to you about information you will need for self-care during a family meeting. The observer may be observing these interactions informally in the waiting room, or during a family meeting with the health care providers. You may ask the observer to leave or not to be present during any conversations/ discussions. This observation

component is optional.

Goal Attainment Scaling: During the interview, a member of the research team will ask you about your personal health goals. The researcher will record these goals and will ask you about them again at the follow-up interview. *note part of this dissertation

Tracking Form: We are asking participants to use a tracking form to record care plans and referrals to other community services. The researcher will use this information to understand what community resources are being used by older adults, and whether participants are being referred to appropriate services.

Assessment Urgency Algorithm (AUA): At the beginning of your appointment, a nurse will ask you questions about your current health situation. This is part of usual care practices. The answers to these questions and associated score will be used for the purpose of the research study.

We are looking for approximately 30 participants and their caregivers to participate in this study.

D. WHERE WILL THE STUDY TAKE PLACE AND WHEN?

The first interview will take place at your primary care location after your appointment today or at a later time convenient for you. A follow-up interview will take place face to face or by telephone in approximately 8-10 weeks. The study will take between 3-6 months.

E. CAN I CHANGE MY MIND ABOUT PARTICIPATING IN THE STUDY?

You may decline to answer any questions, stop the interview or being observed at any time. You may also withdraw from the study at any time by informing one of the researchers. Withdrawal from the study will not affect any of the services or care you or your family/friend receives in any way.

F. RISKS AND BENEFITS

There are no known or anticipated risks associated with your participation. You will not receive any payment or remuneration for participation in the study.

G. CONFIDENTIALITY AND DATA SECURITY

The information you provide will be kept confidential and identified by number only. Your name will not appear in any report or publication resulting from this study. Any quotations used in reports from your interview will be referenced as anonymous.

You have the right to ask the researchers about the data being collected about you for the study and about the purpose of these data. You also have the right to ask the researchers to let you see your personal information and make any necessary corrections to it.

Data collected will be kept securely stored in a locked office for a period of 5 years, and then confidentially destroyed. The answers to the interview will be stored in a locked file cabinet, in a

locked office, at the University of Waterloo. After 5 years, any written notes from the interview will be confidentially shredded and electronic files will be erased after 5 years. Only members of the research team, who have signed a confidentiality agreement regarding information collected during the study, will have access to the study data.

H. QUESTIONS

If at any time you have questions about the proposed research, please contact: the Principal Investigator: Paul Stolee, PhD, School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, 519-888-4567 ext.35879, stolee@uwaterloo.ca or

Student Investigator: Jacobi Elliott, PhD Candidate, School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, 519-888-4567 ext. 38982, j7elliott@uwaterloo.ca

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. The final decision about participation is yours. Should you have any questions or concerns arising from your participation in this study, please contact Dr. Maureen Nummelin, Chief Ethics Officer, at 1-519-888-4567, Ext. 36005 or

Maureen.nummelin@uwaterloo.ca.

What will happen after the study is over?

The researchers will ask if you would like to be contacted in the future to go over the findings and give your opinions on the results. If you do not want to be contacted in the future, you may indicate this preference without penalty and without any consequences to your health care.

I. CONSENT TO PARTICIPATE

I have read the information letter about the study being conducted at my health centre. I know that the study is being conducted by *Jacobi Elliott (PhD Candidate)* from the School of Public Health and Health Systems at the University of Waterloo under the supervision of Dr. Paul Stolee. A portion of the information collected will be used for Jacobi's PhD dissertation.

I was informed that you would like my help to better understand how to engage older adults in their health care and to improve care experiences of myself and others. I was informed that my participation in this study involves:

1. A face-to-face interview in clinic or at a convenient time and a follow-up interview by telephone 8-10 weeks later. I was informed that any quotations taken from my interviews will be referenced as anonymous in any publications of this study.
2. I also understand that my interactions with my caregiver and care provider may be observed but only with my permission.
3. I understand that the researchers will have access to my AUA score
4. I understand that I will be discussing my goals and tracking my care plan in a booklet.

I have made a decision to participate in the research study based on the information I have received in the discussion with the researcher(s) from the University of Waterloo. I have had the

opportunity to ask questions and receive any additional details I wanted about the study. I also understand that I may decline answering any of the questions, if I so choose and I am free to withdraw from the study at any time by telling the researchers that I no longer wish to continue. I understand that the decision to participate or withdraw from the study will not affect the care I receive from my health centre.

All information that I provide will be held in confidence and I will not be identified in any reports or publications resulting from this research. I was informed that any quotations taken from my interview(s) will be referenced as anonymous in any publications of this research.

I was informed that as part of this study the research team may be discussing some of my care experiences with myself and my caregiver.

I was informed that as part of this study, the research team will be observing interactions between me, my family, and my health care providers at my primary care location. For instance, the researcher may observe us exchanging information about care options. I understand that this is optional.

Please note, by signing this consent form you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

(Check the box or boxes indicating the parts of the study you agree to participate in)

- I agree to participate in this study**
- I agree to participate in 2 interviews**
- I agreed to discuss my personal goals and track my care plan in a booklet I give consent for quotations from my interview to be used in reports where they will be referenced as anonymous.**
- I agree to be audiotaped during the interview**
- I agree to have my interactions with health care providers and family members observed.**
- I agree to the researchers having access to my Assessment Urgency Algorithm (AUA) information.**

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

YES, please e-mail me a summary of the results. My e-mail address is:

YES, please mail me a summary of the results. My mailing address is:

NO, I do not wish to receive a summary of results

The research study has been reviewed by and received ethics clearance through a University of Waterloo Research Ethics Committee.

Appendix K. Information Letter and Consent for Caregiver

Study: Risk Assessment and Care Coordination for Older Persons in Primary Care

Principal Investigator: Paul Stolee, PhD; stolee@uwaterloo.ca; 519-888-4567 x35879

Student Investigator: Jacobi Elliott, PhD Student; j7elliott@uwaterloo.ca; 519-888-4567x38982

A. WHAT IS THE PURPOSE OF THIS STUDY?

Seniors are among the largest growing segment of population in Canada, as well as being the greatest users of the healthcare system. Therefore, it is essential to understand the challenges related to health system integration and also, the continuity of care for seniors. The key lies in identifying strengths and gaps in developing an integrated system of care for frail seniors. The aim of this research program is to develop and monitor an integrated primary health care (PHC)-centred approach to improve the assessment and management of older persons with chronic disease (CD). We will learn about care coordination including; referral and care processes, patient and caregiver experiences and engagement in shared decision-making about care, and provider satisfaction.

B. WHO CAN PARTICIPATE?

We are looking for senior patients who attend primary care centres. To get a full picture of what the patient is going through, we would like to speak to the patient's caregiver as well as members of their health care team.

C. WHAT WILL I BE ASKED TO DO?

Interview: We are asking patients and caregivers to individually participate in a face-to-face interview at the primary care centre. We will contact you again via telephone or meet you in the clinic for follow up interviews (8-10 weeks later). The interview will take approximately an hour to complete. Most of the questions that you will be asked will be about your friend/family's experiences with the health care system. Before beginning the interview, you will be asked to confirm that you agree to participate. You will also be asked a few demographic questions (e.g. your age). The interviews will be audio-recorded and we will make use of quotations with your permission. An identifying information will be removed.

Observation: Would also like to ask permission for a member of the research team to observe interactions between you, their friend/family member and their health care providers at the family health team. The observer may be observing these interactions informally in the waiting room, or during a family meeting with the health care providers. You may ask the observer to leave or not to be present during any conversations/ discussions. This observation component is optional.

We are looking for approximately 30 patients and their caregivers to participate in this study.

D. WHERE WILL THE STUDY TAKE PLACE AND WHEN?

The first interview will take place at your health centre. The follow-up interview will take place face to face or by telephone. The study will take between 8-10 weeks.

E. CAN I CHANGE MY MIND ABOUT PARTICIPATING IN THE STUDY?

You may decline to answer any questions, stop going through the interview, or withdraw from the study at any time. Withdrawal from the interview or from the study will not affect any of the services or care you or your family/friend receives in any way. If you wish to withdraw from the study, you can let the interviewer know any time during the interview, or you can call Jacobi at 519-888-4567 x38982.

F. RISKS AND BENEFITS

There are no known or anticipated risks associated with your participation. You will not receive remuneration for participation in the study.

G. CONFIDENTIALITY AND DATA SECURITY

All information you provide is considered completely confidential.

The information you provide will be kept confidential and identified by number only. Your name will not appear in any report or publication resulting from this study. Any quotations used in reports from your interview will be referenced as anonymous.

You have the right to ask the researchers about the data being collected about you for the study and about the purpose of these data.

Data collected will be kept securely stored in a locked office for a period of 5 years, and then confidentially destroyed. The answers to the interview will be stored in a locked file cabinet, in a locked office, at the University of Waterloo for a period of 5 years. After 5 years, any written notes from the interview will be confidentially shredded and electronic files will be erased after 5 years. Only members of the research team who have signed a confidentiality agreement regarding information collected during the study, will have access to the study data.

H. QUESTIONS

If at any time you have questions about the proposed research, please contact the Principal Investigator: Paul Stolee, PhD, School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, 519-888-4567 ext.35879, stolee@uwaterloo.ca or **Student Investigator:** Jacobi Elliott, PhD Candidate, School of Public Health and Health Systems, University of Waterloo, Waterloo, Ontario, 519-888-4567 ext. 38982, j7elliott@uwaterloo.ca

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. The final decision about participation is yours. Should you have any questions or concerns arising from your participation in this study, please contact Dr. Maureen Nummelin, Chief Ethics Officer, at 1-519-888-4567, Ext. 36005 or

What will happen after the study is over?

The researchers will ask if you would like to be contacted in the future to go over the findings and give your opinions on the results. If you do not want to be contacted in the future, you may indicate this preference without penalty and without any consequences to your or your family members health care.

I. CONSENT TO PARTICIPATE

I have read the information letter about the study being conducted at the health clinic. I know that the study is being conducted by **Jacobi Elliott (PhD Candidate)** from the School of Public Health and Health Systems at the University of Waterloo, under the supervision of Dr. Paul Stolee. A portion of the information collected will be used for Jacobi's PhD dissertation. I was informed that you would like my help to understand the care experiences of my friend/family member.

I was informed that my participation in this study involves:

1. Two face to face interviews (or by telephone). These interviews will take place over a 3 month period and will be recorded. I was informed that any quotations taken from my interviews will be referenced as anonymous in any publications of this study.
2. I am also aware that interactions with my loved one/friend and health care provider may be observed by the researcher. I understand that this part of the research study is optional.

I have had the chance to ask questions related to this study. I have had the chance to receive satisfactory answers to my questions and any additional details I wanted. I was informed that I am free to withdraw from the study at any time by telling the researchers that I no longer wish to continue. I know that if I change my mind about participating there will be no penalty.

Please note, by signing this consent form you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

(Check the box or boxes indicating the parts of the study you agree to participate in)

- I agree to participate in this study**
- I agree to participate in 1 or 2 interviews**
- I give consent for quotations from my interview to be used in reports where they will be referenced as anonymous.**

- I agree to be audiotaped during the interview
- I agree to have my interactions with health care providers and family members observed.

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

YES, please mail me a summary of the results. My mailing address is: _____

NO, I do not wish to receive a summary of results

The research study has been reviewed by and received ethics clearance through a University of Waterloo Research Ethics Committee.

Appendix L: Observation Guide

Date: _____

Time: _____

Observer name:

Location:

Participant Number:

Individuals being observed (*check all that apply*):

- Patient
- Nurse
- Doctor
- Allied Health Professional
- Patient's family member(s)
 - Please list (e.g. daughter, son, sister, brother):

Other: _____

Nature/purpose of interaction (e.g. family conference):

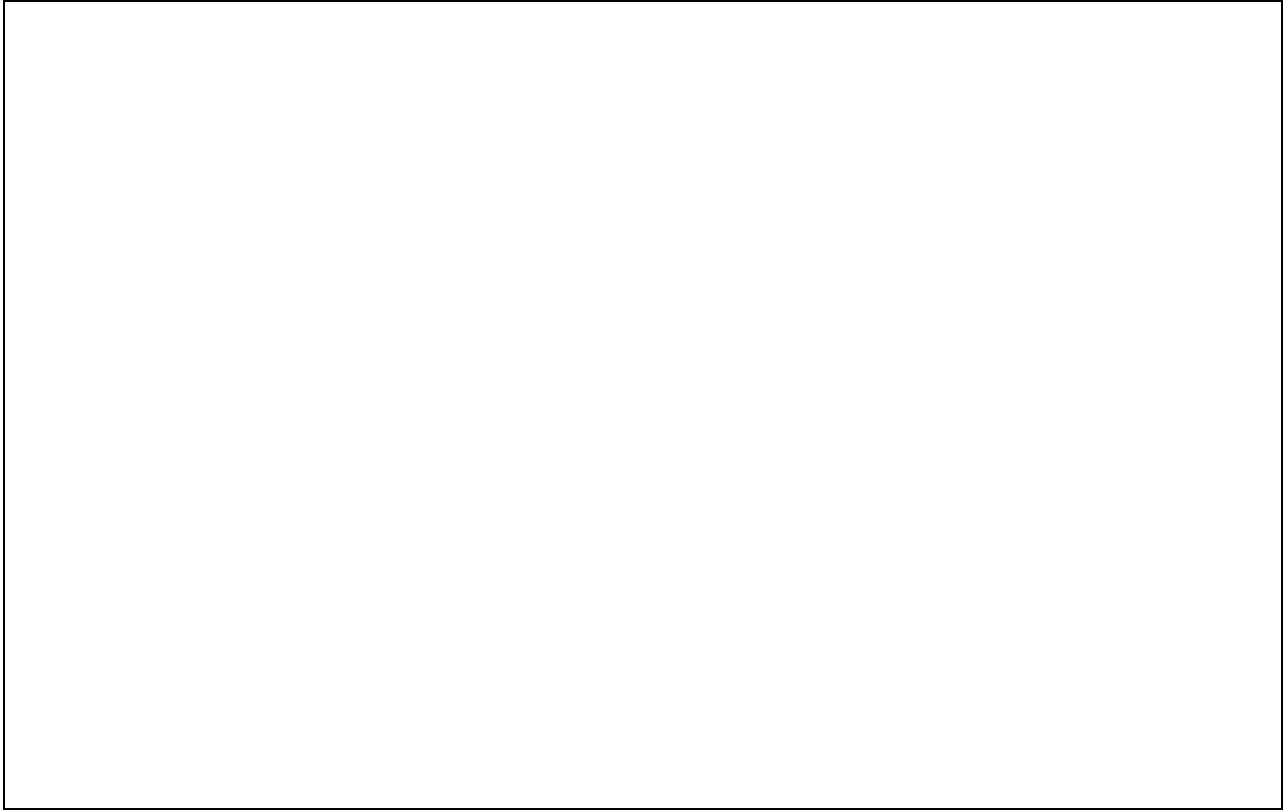
Notes about participants (e.g. mood, communication ability):

a) Please describe the *mood* of the participants?

b) Please describe the *communication styles/ability* of the participants?

Information being shared (e.g. referrals to other services, discharge locations, medications, follow-up programs such as exercise regimens):

Specific documents being provided/exchanged:

A large, empty rectangular box with a thin black border, intended for recording specific documents provided or exchanged.

Additional observations (e.g. did information appear to be understood/opportunity for questions):

A large, empty rectangular box with a thin black border, intended for recording additional observations or questions.

Appendix M: Research Ethics Board - Approval

UNIVERSITY OF WATERLOO
OFFICE OF RESEARCH ETHICS

Notification of Ethics Clearance of Application to Conduct Research with Human Participants

Faculty Supervisor: Paul Stolee	Department: Health Studies & Gerontology
Faculty Supervisor: George Heckman	Department: Health Studies & Gerontology
Student Investigator: Jacobi Elliott	Department: Health Studies & Gerontology

ORE File #: 20452

Project Title: Risk Assessment and Care Coordination for Older Adults in Primary Care


This certificate provides confirmation the above project has been reviewed in accordance with the University of Waterloo's Guidelines for Research with Human Participants and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. This project has received ethics clearance through a University of Waterloo Research Ethics Committee.

Note 1: *This ethics clearance is valid for one year from the date shown on the certificate and is renewable annually. Renewal is through completion and ethics clearance of the Annual Progress Report for Continuing Research (ORE Form 105).*

Note 2: *This project must be conducted according to the application description and revised materials for which ethics clearance has been granted. All subsequent modifications to the project also must receive prior ethics clearance (i.e., Request for Ethics Clearance of a Modification, ORE Form 104) through a University of Waterloo Research Ethics Committee and must not begin until notification has been received by the investigators.*

Note 3: *Researchers must submit a Progress Report on Continuing Human Research Projects (ORE Form 105) annually for all ongoing research projects or on the completion of the project. The Office of Research Ethics sends the ORE Form 105 for a project to the Principal Investigator or Faculty Supervisor for completion. If ethics clearance of an ongoing project is not renewed and consequently expires, the Office of Research Ethics may be obliged to notify Research Finance for their action in accordance with university and funding agency regulations.*

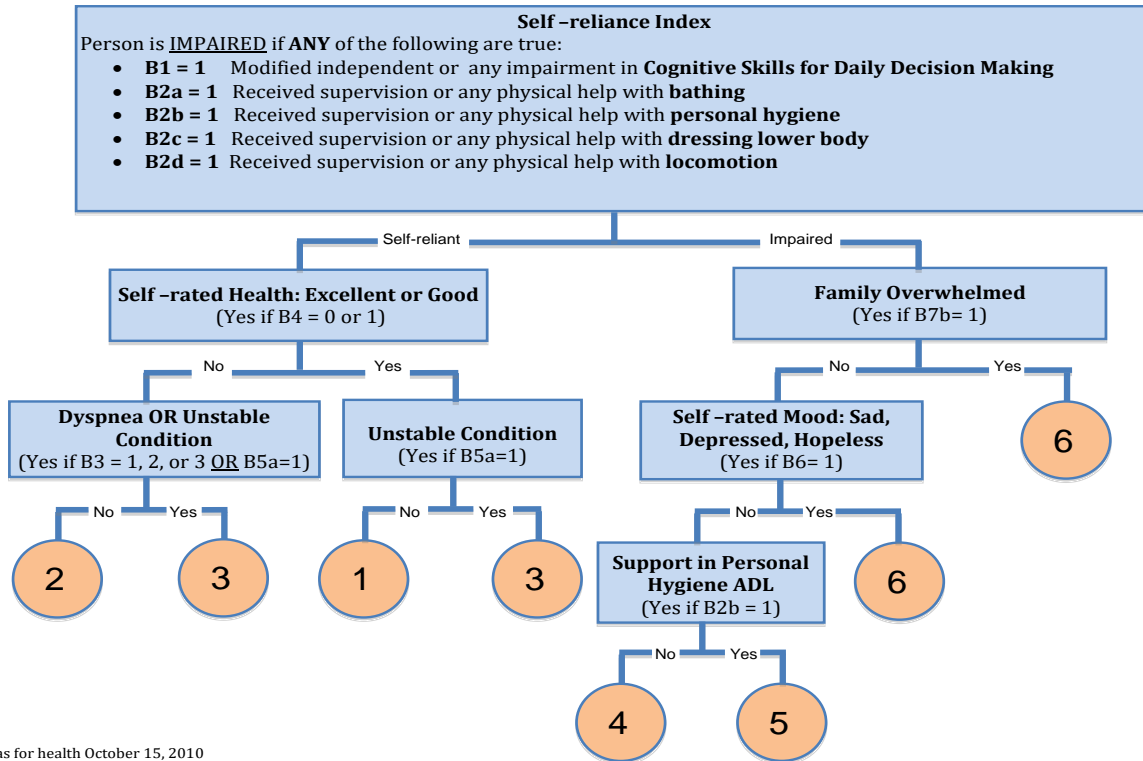
Note 4: *Any unanticipated event involving a participant that adversely affected the participant(s) must be reported immediately (i.e., within 1 business day of becoming aware of the event) to the ORE using ORE Form 106. Any unanticipated or unintentional changes which may impact the research protocol must be reported within seven days of the deviation to the ORE using ORE form 107.*


Maureen Nummelin, PhD
Chief Ethics Officer

Date

1/29/2015

Appendix N: Assessment Urgency Algorithm



ideas for health October 15, 2010