

DIABETES AND URINARY INCONTINENCE IN OLDER HOME-CARE CLIENTS

UNDERSTANDING THE COMPLEXITY OF DIABETES AND URINARY
INCONTINENCE IN OLDER ADULTS WITH MULTIPLE CHRONIC CONDITIONS
RECEIVING HOME CARE: A MIXED-METHODS STUDY

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the
Requirements for the Degree Doctor of Philosophy

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TITLE: Understanding the complexity of diabetes and urinary incontinence in older adults with multiple chronic conditions receiving home care services: A mixed-methods study

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LAY ABSTRACT

Many older adults with diabetes have urinary incontinence that is emotionally and physically bothersome. These older adults also receive home-care services. In this study, older adults were asked about how they care for their diabetes and incontinence and how their home-care workers help them with this care. Nurse participants were asked how they help older adults with diabetes and incontinence and the challenges they face. The results of home-care assessments done in Ontario were also analyzed to learn how common incontinence is in older adults with diabetes and factors associated with having incontinence. The study found many factors, such as living with many chronic conditions and lack of finances, as well limited home-care service provision and the task-focus of home care created challenges for these older adults. The findings can help in making changes to home-care service delivery to improve care for older adults and their caregivers.

ABSTRACT

Urinary incontinence (UI) is a common complication of type 2 diabetes mellitus (T2DM) for older adults (≥ 65 years) that is associated with reduced quality of life and risk of institutionalization. This convergent, mixed methods research study, informed by a model of clinical complexity, explored the complexities for older adults living with UI and T2DM, and home-care nurses providing care to this population in Ontario. In the quantitative strand, the most recently completed Resident Assessment Instruments for Home Care from 2011-2016 for older home-care clients with diabetes were analyzed to determine the prevalence and correlates of UI. The qualitative strand used interpretive description methodology to explore the experiences of 18 older adults living with T2DM and UI receiving home-care services and the experiences of 15 home-care nurses caring for this population. These data sources were converged to describe the factors that contributed to complexity for older adults with UI and T2DM: (a) challenges of living with multiple chronic conditions (MCC), medical instability, and high care needs; (b) financial barriers; (c) lack of understanding of older adults' values and preferences by health-care providers; (d) caregiver burden; and (e) functional impairments. The health-care system contributed to this complexity through: (a) inadequate and minimal provision of nursing and interprofessional home-care services; (b) task-focused structure of home care; (c) minimal interprofessional collaboration; (d) lack of an integrated communication system; and (e) lack of navigation to community resources. Providing health-promoting care for older adults with UI and T2DM requires a system-wide enactment of integrated care that takes both a person- and family-centred care and social determinants of health

approach. Interventions for older adults with MCC should involve standardized and comprehensive assessment, care coordination, enhanced nursing service provision, and interprofessional team collaboration to attend to the dimensions of complexity and ensure the needs of older adults and their caregivers are met.

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Table of Contents

LAY ABSTRACT	iii
ABSTRACT.....	iv
ACKNOWLEDGEMENTS	vi
LIST OF FIGURES	xiii
LIST OF TABLES	xiv
LIST OF ABBREVIATIONS.....	xvi
DECLARATION OF ACADEMIC ACHIEVEMENT	xix
CHAPTER ONE	1
Introduction	1
Purpose of the Study and Overall Research Process.....	3
Research Questions	4
Quantitative Strand Research Questions	5
Qualitative Strand Research Questions	5
Overarching Mixed Methods Research Question.....	5
Conceptual Framework	5
Background and Context.....	9
The Burden of Diabetes in Older Adults	9
Diabetes and Urinary Incontinence in Older Adults	12
Home-Care Services for Older Adults with Diabetes and Urinary Incontinence.....	16
Personal Statement of Disciplinary Orientation and Assumptions	20
Thesis Content.....	21
References	24
CHAPTER TWO	36
Literature Review	36
Introduction	36
Search Strategy and Methods	37
Quality Assessment	39
Results	39
Prevalence and Correlates of Urinary Incontinence in Older Adults with Diabetes.....	39
Experiences of Older Adults Living with Diabetes and Urinary Incontinence	41

Experiences of Home-Care Nurses Caring for Older Adults with Diabetes and Urinary Incontinence	46
Discussion	50
Conclusion.....	53
References	55
CHAPTER THREE	76
Abstract	77
What is Already Known?	78
What This Paper Adds?	78
Keywords.....	78
Introduction	79
Background	80
Objectives.....	83
Method	83
Convergent Mixed Methods Research Design	83
Significance and Implications	95
Conclusion.....	96
Declaration of Conflicting Interests	97
Funding.....	97
References	108
CHAPTER FOUR.....	120
Abstract	121
Introduction	123
Methods.....	125
Design and Setting.....	125
Sample	127
Variables.....	127
Statistical Methods	129
Results	131
Discussion	133
Implications	135
Strengths and Limitations.....	137
Conclusions	137

Acknowledgements	138
Author Contributions	138
Author Disclosures	138
Funding	139
References	140
CHAPTER FIVE	161
Abstract	162
Introduction	163
Method	165
Interpretive Description Design.....	165
Researcher Characteristics and Reflexivity	166
Setting and Sample	167
Data Collection	168
Data Analysis.....	168
Techniques to Enhance Trustworthiness	169
Ethics	170
Results	170
Description of the Older Adult Participants	170
The Experience of Living with Diabetes and Urinary Incontinence for Older Adults Receiving Home-Care Services.....	172
Discussion	185
Implications	189
Study Strengths and Limitations.....	190
Conclusion.....	191
Conflict of Interest.....	191
Funding	191
Acknowledgements	192
References	193
CHAPTER SIX.....	197
Abstract	198
Introduction	200
Methods.....	201
Study Design.....	201
Setting and Sampling.....	203
Data Collection	204

Data Analysis.....	204
Trustworthiness	205
Ethical Considerations	206
Findings	206
Description of the Nurse Participants	206
Home-Care Nurses’ Care of Older Adults with Diabetes and Urinary Incontinence	207
Discussion	220
Implications	224
Study Strengths and Limitations.....	225
Conclusion.....	226
Conflict of Interest.....	226
Funding.....	227
Acknowledgments	227
References	228
CHAPTER SEVEN	235
Mixed Methods Analysis and Interpretation.....	235
Introduction	235
Mixed-Methods Analysis	236
Mixed Methods Synthesis	237
Person and Social Support Side of the Need-Services Gap.....	237
Services Side of the Need-Services Gap	242
Mixed-Methods Interpretation	245
Conclusion.....	245
References	247
CHAPTER EIGHT	255
Discussion	255
Introduction	255
Summary of Main Findings	255
Implications	259
Implications for Nursing and Interprofessional Practice	260
Implications for Education	270
Implications for Policy and Health-Care Service Delivery	274
Implications for Research.....	278

Strengths and Limitations of the Study	280
Strengths and Limitations of Conceptual Framework	283
Conclusions	284
References	285

LIST OF FIGURES

CHAPTER ONE:

Figure 1. Conceptual Model of the Role of Complexity	7
--	---

CHAPTER THREE:

Figure 1. Diagram of the Proposed MMR Study	102
---	-----

CHAPTER SIX:

Figure 1. Thematic Conceptualization of the Findings	208
--	-----

LIST OF TABLES

CHAPTER TWO

Table 1. Subject Headings and Keywords Included in Literature Searches	61
Table 2. Critical Appraisal of Studies in Quantitative Literature Review	62
Table 3. Critical Appraisal of Studies in Qualitative Literature Review	63
Table 4. Studies Examining the Prevalence and Correlates of Incontinence in Older Adults with Diabetes	65
Table 5. Studies Exploring the Experiences of Older Adults Living with Diabetes	66
Table 6. Studies Exploring the Experiences of Older Adults Living with Urinary Incontinence	70
Table 7. Studies Exploring the Experiences of Home-Care Nurses Caring for Clients with Diabetes	72
Table 8. Study Exploring the Experiences of Home-Care Nurses Caring for Older Adults with Urinary Incontinence	75

CHAPTER THREE

Table 1. RAI-HC Health Outcome Scales	103
Table 2. Definitions of Urinary Continence in Proposed Study and the RAI-HC	104
Table 3. Corresponding RAI_HC Items to Assess Characteristics and Health Service Utilization of Older Adults Receiving Home Care Services	105
Table 4. Joint Display of Quantitative and Qualitative Analysis	107

CHAPTER FOUR

Table 1. Total Population Characteristics and Characteristics Associated with Urinary Incontinence in Older Adults with Diabetes Receiving Home Care	148
Table 2. Factors Significantly Associated with Urinary Incontinence in Older Home Care Clients with Diabetes: Multivariable Logistic Regression Results	151

CHAPTER FIVE

Table 1. Demographic and Clinical Characteristics	171
---	-----

CHAPTER SIX

Table 1. Interpretive Description Process of Analysis	205
---	-----

Table 2. Nurse Participants' Demographic Characteristics	207
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CHAPTER SEVEN

Table 1. Joint Display of Quantitative and Qualitative Data and Mixed Methods Interpretation of Results	249
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CHAPTER EIGHT

Table 1. Joint Display of Mixed Methods Study Results and Intervention Components	297
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LIST OF ABBREVIATIONS

A1C	glycated hemoglobin
ADL	activities of daily living
AGS	American Geriatrics Society
CAP	Clinical Assessment Protocol
CCF	Canadian Continence Foundation
CHCA	Canadian Home Care Association
CHESS	Changes in Health End-Stage Disease and Signs and Symptom
CIHI	Canadian Institute for Health Information
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CASP	Critical Appraisal Skills Programme
CI	confidence interval
CPP	Canada Pension Plan
CPS	Cognitive Performance Scale
DRS	Depression Rating Scale
ER	emergency room
IADL	instrumental activities of daily living

IDF International Diabetes Federation

interRAI HC. inter Resident Assessment Instrument for Home Care

LHIN Local Health Integration Network

MAPLe Method for Assessing Priority Levels

MMR mixed methods research

MOHLTC Ministry of Health and Long-term Care

MCC multiple chronic conditions

NCA nurse continence advisor

OACCAC Ontario Association of Community Care Access Centres

OHTAC Ontario Health Technology Advisory Committee

OHCA Ontario Home Care Association

OR odds ratio

OT occupational therapist

PSW personal support worker

PT physiotherapist

QUAL qualitative strand

QUAN quantitative strand

RAI-HC Resident Assessment Instrument for Home Care

RN registered nurse

RNAO Registered Nurses' Association of Ontario

RPN registered practical nurse

SD standard deviation

T2DM type 2 diabetes mellitus

UI urinary incontinence

WHO World Health Organization

DECLARATION OF ACADEMIC ACHIEVEMENT

This thesis contains four manuscripts regarding original research that have been published or submitted for publication. The manuscripts presented in Chapters 3 through 6 are co-authored. Melissa Northwood (student) is the first author, and contributed to the conception and design of the study, the acquisition of the quantitative data and the conduction of interviews, the analysis of both qualitative, quantitative data, and mixed methods interpretation, and the writing and revising of each manuscript. Dr. Jenny Ploeg (supervisor) contributed to the conception and design of the study, participated in the qualitative analysis process, and revised the manuscripts critically. The two supervisory committee members, Drs. Maureen Markle-Reid and Diana Sherifali, contributed to the conception and design of the study, reviewed the analyses, and critically revised the manuscripts. Dr. Kathryn Fisher reviewed the quantitative analysis and critically revised the manuscript presented in Chapter 4. The results of this thesis have been presented at two national conferences:

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CHAPTER ONE

Introduction

Diabetes mellitus is a serious metabolic disorder with life threatening and functionally detrimental complications (Houlden, 2018; Punthakee, Goldenberg, & Katz, 2018). Type 2 diabetes mellitus (T2DM) accounts for 90% to 95% of diabetes in Canada and worldwide (Gruneir et al., 2016; Public Health Agency of Canada, 2017). T2DM affects between 14% to 23% of older adults (aged ≥ 65 years) and an even greater proportion—25%—of older adults receiving home-care services (Gruneir et al., 2016; Vetrano et al., 2016). The majority of older adults with T2DM (90%) are living with multiple chronic conditions (MCC) defined as two or more health conditions that require ongoing health-care attention and impact activities of daily living (Boyd & Fortin, 2010; Gruneir et al., 2016). T2DM is associated with complications such as vascular disease, chronic kidney disease, retinopathy, cognitive dysfunction, and depression (Sherifali & Meneilly, 2016; Sinclair et al., 2012; Vetrano et al., 2016).

Older adults with T2DM are at an increased risk for poor outcomes, including higher mortality, reduced functional status, and increased risk of institutionalization compared to older adults who do not have T2DM (American Geriatrics Society [AGS], 2013; Kirkman et al., 2012). Urinary incontinence (UI) is a common but under-recognized complication of T2DM and therefore under-researched and under-treated (AGS, 2013; Brown et al., 2005). In Ontario, the provincial average of home-care clients who have newly developed bladder incontinence or whose bladder function has not

improved since their previous assessment has increased from 48% in 2009/2010 to 60% in 2014/2015 (Health Quality Ontario, 2017).

Despite the large population of older adults with T2DM receiving home-care services, the complexities of managing T2DM in this sector has not received significant research attention (Hsu et al., 2014). Home care is defined as services “provided in the home and community setting, that encompass health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for the family caregiver” (Better Home Care in Canada Partners, 2016, p. 120). There is little evidence of how to best provide care for older adults with T2DM receiving home-care services (Meneilly et al., 2018; Sinclair et al., 2012). Furthermore, there is not a consistent approach to diabetes care in current home-care nursing practice as is practice in outpatient settings across Ontario, in the form of Diabetes Education Programs. In these programs, clients can receive services from nurses and other Certified Diabetes Educators regarding diabetes education and support, counselling, and care plans to minimize symptoms (Government of Ontario, 2019). Quality improvement programs in the home-care setting have not focused on a comprehensive approach to diabetes management but rather, for example, the timely healing of diabetic foot ulcers (Hamilton Niagara Haldimand Brant Local Health Integration Network [LHIN], 2018).

Home-care nurses are well positioned to address the clinical complexity of managing T2DM and UI as they lead and coordinate the care in this setting (Canadian Home Care Association [CHCA], 2013). Within this role, home-care nurses have the

potential to play an important role in preventing complications, functional decline, and use of other, more expensive services, such as hospitalization or long-term care placement for older adults with both T2DM and UI (Kirkman et al., 2012; Rubin, 2015). However, little is known about how to best provide care to this population. Further knowledge is needed regarding the experiences of home-care nurses who care for older adults with T2DM and UI, and of the older adults with T2DM and UI who receive home-care services. Furthermore, very little is known about the prevalence and correlates of UI in older adults with T2DM receiving home care (Hsu et al., 2014). Given the high prevalence of older adults with T2DM receiving home-care services, the potential for negative outcomes including urinary incontinence, and the key position home-care nurses have in mitigating these outcomes, further research is required.

This chapter will detail the purpose and overall research process, research questions, background and context of the study, personal statement of disciplinary orientation, and thesis content.

Purpose of the Study and Overall Research Process

The purpose of this mixed methods study was to better understand the complexity of living with T2DM and UI in older adults who receive home-care services. A convergent, mixed methods design was used, informed by a complexity conceptual model, to address this research objective (Creswell & Plano Clark, 2018; Grembowski et al., 2014). Individual semi-structured interviews were conducted with older adults who receive home-care services to explore how T2DM and UI are experienced, and with

home-care nurses to gain their perspectives on providing care to these older adults. Administrative data from the Resident Assessment Instrument for Home Care (RAI-HC) was used to assemble a cohort of individuals from Ontario over age 65 receiving home-care services to determine the prevalence and correlates of UI (sociodemographic, psychosocial, functional, and clinical characteristics) in older adults with T2DM (Morris et al., 2012). A mixed methods research approach was used to converge the multiple data sources and enable a comprehensive analysis of the problem that could not be obtained by either type of data alone (Creswell & Plano Clark, 2018). The converged data were analyzed and synthesized to provide a deeper understanding of the problem and implications for the provision of home-care services to this population in the form of empirically and experientially informed intervention components (Sidani & Braden, 2011). This research is crucial to identify challenges and optimal strategies to manage T2DM and UI in the home-care setting and to improve the quality and experience of care for this population at risk for negative health outcomes.

Research Questions

In order to carefully examine the problem of T2DM and UI in a home-care population of older adults, independent and overarching research questions were posed (Creswell & Plano Clark, 2018). For this convergent design, independent questions were asked for the quantitative and qualitative strands and associated sub-questions, as well as an overarching and integrated mixed methods research question (Creswell & Plano Clark, 2018; Tashakkori & Creswell, 2007).

Quantitative Strand Research Questions

Among older adults (aged ≥ 65 years) with T2DM receiving home-care services in Ontario:

1. What is the prevalence of UI?
2. Are there differences in the sociodemographic, psychosocial, functional, and clinical characteristics between those with UI and those with no known UI?
3. What are the sociodemographic, psychosocial, functional, and clinical characteristics associated with UI?

Qualitative Strand Research Questions

1. How are T2DM and UI experienced by older adults aged 65 years and older receiving home-care services?
2. How do home-care nurses care for older adults with T2DM and UI?

Overarching Mixed Methods Research Question

What are the components of complexity experienced in the home-care context by older adults with T2DM and UI and the nurses who care for them, and how could an understanding of these components inform care approaches for this group of older adults?

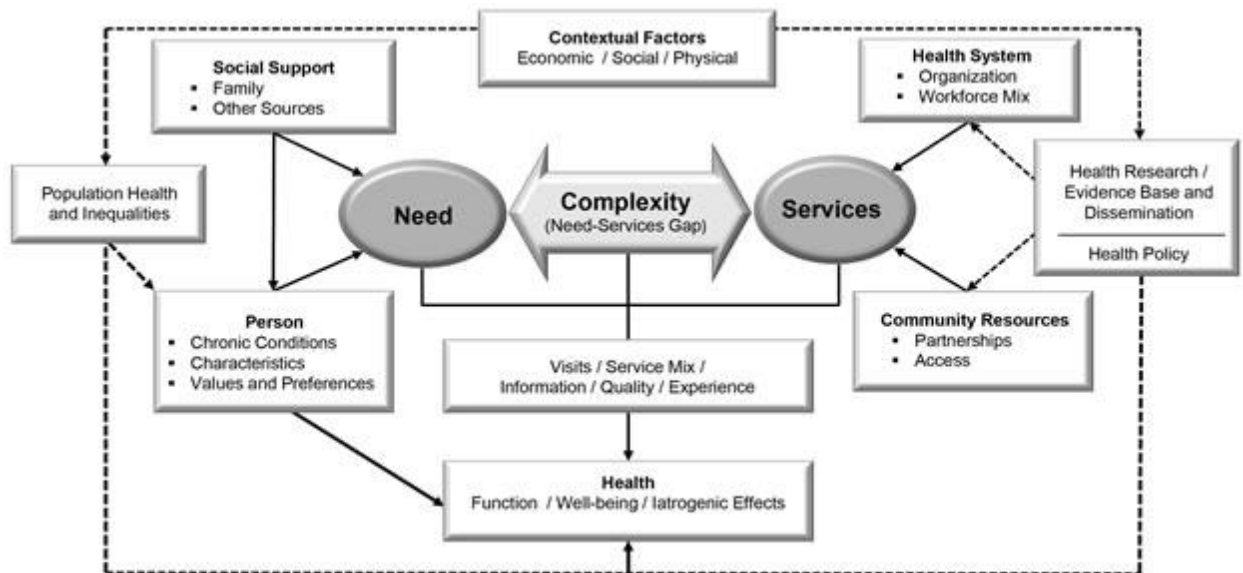
Conceptual Framework

The interconnected challenges of living with MCC create clinical complexity, which has been conceptualized in a complexity model developed by Grembowski and colleagues (2014) to guide research in this area. The authors of this model were part of an

MCC research network in an American governmental agency for health-care research and quality (Grembowski et al., 2014). The model was generated through reference to current medical, public-health, and epidemiological literature, as well as expert consultation and consensus-building among the research network (Grembowski et al., 2014). Although not explicitly stated, the authors' call for an "epistemological shift from a reductionist single-condition paradigm to one that accounts for inherent complexity" reveals a constructivist, philosophical approach (Grembowski et al., 2014, p. S7). This constructivist stance of experience or truth being relative, multiple, and socially constructed is revealed in the discussion of the social, contextual, and policy influences on MCC (Guba & Lincoln, 1994). Also, the authors describe the model as "ecological," suggesting it may be informed by ecological theory that acknowledges the interrelationships between individuals and their biological, psychological, and behavioural characteristics, and the physical, social, and cultural aspects of their environments (Bartholomew Eldredge et al., 2016).

The model defines clinical complexity as "the gap between the major system components: an individual's *needs* and the *capacity* [emphasis added] of the health care system to support those needs" (Grembowski et al., 2014, p. S10). The size and nature of this gap is affected by the main interacting components in the model: the health-care system, individual characteristics of the person, social supports, and community resources (as seen in Figure 1; Grembowski et al., 2014). As both health and the health-care system are influenced by the broader context, the model also includes economic,

social, and physical contextual factors and health-care policies that influence population health and inequities (Grembowski et al., 2014).



*Figure 1. Conceptual Model of the Role of Complexity. From “A conceptual model of the role of complexity in the care of patients with multiple chronic conditions,” by D. Grembowski, J. Schaefer, K. E. Johnson, H. Fischer, S. L. Moore, M. Tai-Seale, ... L. LeRoy, 2014, *Medical Care*, 52(3), p. S10. Copyright 2014 by Lippincott Williams & Wilkins. Reprinted with permission.*

The needs of older adults with MCC are influenced by the social support systems of their family and other caregivers (Grembowski et al., 2014). Their needs are also influenced by the number, severity, and duration of the chronic conditions and the concordance (similar underlying pathophysiology and management approach) or discordance (unrelated in pathophysiology or management approach) of the conditions and the individual’s capacity to engage in self-management (Grembowski et al., 2014). Other personal factors that impact needs include gender, age, socioeconomic status, ethnicity, race, and social deprivation (Grembowski et al., 2014).

The ability of the system to meet patient needs is influenced by components of the health-care system and community resources (Grembowski et al., 2014). Factors within the health-care system that impact service delivery include the organization of the system, the workforce mix, and that workforce's knowledge and expertise regarding MCC (Grembowski et al., 2014). Community resources can impact service delivery through access to these services and the presence of partnerships between the health-care system and these resources (Grembowski et al., 2014).

This conceptual model (Grembowski et al., 2014) is a practical tool to structure the exploration of the challenges that face older adults living with and managing T2DM and UI while receiving home-care services as it provides a framework to consider many of the interacting components that could influence health outcomes for this population. Previous research on MCC has not consistently considered the broader social determinants of health or the social, political, and economic context that influences access to health care and health and well-being (Northwood, Ploeg, Markle-Reid, & Sherifali, 2017). The model was used to inform: selection of variables in the quantitative strand, selection of variables for regression modeling, development of the interview guides in the qualitative strand, initial consideration of data in the “sorting and organizing” phase of qualitative analysis, and creation of the joint display for the mixed methods analysis and interpretation.

Background and Context

The Burden of Diabetes in Older Adults

Diabetes is a global public health burden as older adults with T2DM are using more health-care resources, the prevalence of T2DM is steadily increasing every year, and the prevalence of T2DM increases with age (Canadian Institute for Health Information [CIHI], 2009; International Diabetes Federation [IDF], 2013). T2DM is classified by the Canadian Diabetes Association as ranging from mainly insulin resistance with relative insulin shortage to a predominant secretory defect with insulin resistance (Punthakee et al., 2018).

As noted earlier, older adults with T2DM are living with MCC as recent evidence in Ontario reported that 90% of older adults with T2DM had at least one other chronic condition, and 40% had five or more chronic conditions (Gruneir et al., 2016). A population-based study found that older adults receiving home-care services in Ontario have an average of four chronic conditions (Mondor et al., 2016), and health-related quality of life decreased incrementally with each additional chronic condition (Mondor et al., 2016). In a sample of older adults with T2DM using home-care services across Europe and Ontario, 69% had on average two geriatric syndromes—clinical conditions in older adults that cannot be understood as discrete diseases—such as falls and delirium (Vetrano et al., 2016). The presence of other chronic conditions particularly cognitive impairment and depression, challenge older adults' ability to self-manage their T2DM (Sherifali & Meneilly, 2016). Older adults with MCC experience poorer outcomes—such

as lower levels of quality of life, and increased disability, functional decline, and dependence on informal caregivers—compared to those without MCC (Boyd & Fortin, 2010; Marengoni et al., 2011). Thus, the aggregate effects of MCC in older adults with T2DM must be considered both clinically and in research (Boyd & Fortin, 2010; Grembowski et al., 2014).

The experience of having T2DM is affected by multiple contextual factors (Grembowski et al., 2014; Hankivsky & Cormier, 2009). For example, successful management of T2DM is influenced by multiple individual factors, including gender, age, and socioeconomic status, as well as the intersections of these and other social categories that can produce advantages or health inequities, such as lack of access to health care services or preventative care (Davitt, 2012; Grembowski et al., 2014; Hankivsky & Cormier, 2009; Warner & Brown, 2011). For example, Canadian adults in the lowest income group were twice as likely to have diabetes as those in the highest income group (CIHI, 2009). In turn, higher income adults with diabetes were twice more likely to receive recommended care than adults with lower incomes (CIHI, 2009).

Health-care providers often find it challenging to provide care to older adults with T2DM as the progression of chronic conditions involves complicated and often competing treatments for single conditions (Boyd & Fortin, 2010; Grembowski et al., 2014). For example, safely self-administering insulin can be threatened by memory impairment related to dementia. Furthermore, health care for older adults is often fragmented by provider (i.e., different specialists), location (i.e., hospital, home, primary

care), and sector (i.e., volunteer community support services; Bayliss et al., 2014; Grembowski et al., 2014).

Health and social policies additionally affect older adults with T2DM. In Canada, many older adults with T2DM require health services in the home setting; however, home care is recognized but not funded as part of a national, universal health-care system of Medicare under the *Canada Health Act* of 1984 (Donner et al., 2016). As such, provincial governments have structured home care as a mix of public, voluntary, and commercial providers that are not universally accessible or completely publicly funded (Donner et al., 2016). Collectively, these challenges create clinical complexity, defined in the complexity model as a gap between the needs of older adults and the health-care system's ability to meet those needs (Grembowski et al., 2014). The consequence of this gap is that older adults with T2DM may not receive the health and social support they require to manage their health and prevent complications while remaining living in their own homes.

Internationally, best practice guidelines for the management of T2DM in older adults recommend comprehensive care that includes self-management education and support regarding glycemic control, physical activity and exercise, nutrition, and weight control (Houlden, 2018; IDF, 2013; Kirkman et al., 2012). Self-management education is defined as a “systematic intervention that involves active participation by the individual in self-monitoring of health parameters and/or decision-making with the application of knowledge and skills” (Sherifali et al., 2018, p. S36). Recommended as part of this comprehensive care is screening for and management of complications, including

cardiovascular disease, dyslipidemia, renal impairment, retinopathy, neuropathy, foot disease, and erectile dysfunction (Houlden, 2018; IDF, 2013; Kirkman et al., 2012).

Older adults with T2DM are encouraged to learn how to perform an array of skills to manage glycemic control, monitor symptoms, and solve problems as they arise (Meneilly et al., 2018). Self-management education, delivered by nurses and other health-care providers, has proven effective in improving health outcomes for adults with T2DM (Sherifali et al., 2018).

However, existing guidelines do not suggest screening for UI or provide direction on how to manage UI in older adults with T2DM. Additionally, these guidelines do not consider the impact of the social determinants of health on living with diabetes, except for noting racial or ethnic differences in preferences for treatment (Kirkman et al., 2012). Further research is needed to understand the experience of living with T2DM and UI and how home-care nurses care for this group in order to inform a model of health-care delivery for older adults with T2DM and UI (Sherifali & Meneilly, 2016).

Diabetes and Urinary Incontinence in Older Adults

UI is defined by the International Continence Society as the involuntary leakage of urine (Abrams et al., 2002). The Canadian Bladder survey found that 5.4% of male and 28.8% of female community-dwelling older adults (aged ≥ 65) experienced urgency, stress, or mixed UI (Herschorn et al., 2007). Research in adults of all ages has demonstrated that over 50% of men and women with diabetes have lower urinary tract symptoms, including incontinence (Brown et al., 2005).

While UI would not be considered a life-threatening complication of T2DM, it has a debilitating impact on the health, function, and quality of life of older adults (Canadian Continence Foundation [CCF], 2014; Coyne et al., 2013). Older adults with UI are 1.5 times more likely to have depressive symptoms than those without UI, and 43% of older adults with UI report depressive symptoms (Dugan et al., 2000). Older adults experiencing UI are also at risk for social isolation, falls, and fractures (CCF, 2014; Chiarelli et al., 2009; Coyne et al., 2013). UI is also a risk factor for decreased physical activity and, as such, contributes to functional decline in older adults (Coll-Planas, Denking, & Nikolaus, 2008). Incontinence-associated dermatitis and pressure injuries are associated with UI (Cottenden et al., 2017). There is also an impact on health-care system resources; incontinence is a significant predictor of long-term care institutionalization and older adults with UI are more likely to become hospitalized (CCF, 2014; Wagg et al., 2017).

UI is a complex problem associated with multiple factors in older adults, including age-related changes, medications, environmental factors, and MCC (Wagg et al., 2017). Age-related changes that impact UI are: (a) decreased bladder capacity, (b) decreased sensation of filling, (c) increased residual urine, (d) increased incidence of prostatic enlargement in men, (e) decreased estrogen in women, (f) weakened pelvic floor muscles, (g) increased night-time urine production, and (h) increased white matter hyperintensities in the brain (Wagg et al., 2017). Older adults often take several prescription medications which can affect bladder emptying and urine production (Wagg et al., 2017). Environmental factors that contribute to UI include the need for assistance

when toileting, accessible washrooms, and fluid intake practices such as adequate hydration and avoidance of caffeine (Dumoulin et al., 2017; Wagg et al., 2017).

Older adults' continence status is also affected by the consequences of chronic conditions, such as reduced cognitive function in dementia, mobility impairments caused by arthritis or a progressive neurological disease, or direct effect on urine production, such as untreated sleep apnea (Wagg et al., 2017). Chronic conditions associated with UI include: (a) diabetes mellitus, (b) degenerative joint disease, (c) chronic pulmonary disease, (d) congestive heart failure, (e) sleep apnea, (f) constipation, (g) obesity, (h) stroke, (i) Parkinson's disease, (j) normal pressure hydrocephalus, (k) dementia, and (l) depression (Dumoulin et al., 2017; Wagg et al., 2017).

T2DM and UI can be considered concordant conditions as they share underlying causal mechanisms (Boyd & Fortin, 2010; Brown et al., 2005). There is biological evidence of this connection as the physiological, microvascular, and neurological complications of T2DM impact the continence mechanism and create problems in bladder storage and emptying (Daneshgari et al., 2009; Lifford et al., 2005). This translates into difficulties with increased bladder instability or decreased contractility, both of which can cause UI (Daneshgari et al., 2009). Additionally, hyperglycemia may lead to polyuria, which contributes to nocturia and UI. Older adults with T2DM are also at increased risk of urinary tract infections—a common, reversible cause of UI in older adults—through a number of mechanisms, such as glucosuria promoting bacterial growth and incomplete bladder emptying (Gomez, Kanagarajah, & Gousse, 2011; Registered Nurses' Association of Ontario [RNAO], 2011).

UI is a treatable condition with research evidence indicating that it is amenable to structured, nurse-led interventions (Bliss, Westra, Savikm, & Hou, 2013; Moore et al., 2003; Dumoulin et al., 2017; Ontario Health Technology Advisory Committee [OHTAC], 2008; Northwood & Skelly, 2014; Williams et al., 2005). These nurse-led interventions can be self-directed behavioural interventions, such as fluid intake changes or pelvic floor muscle exercises, or caregiver-directed interventions, such as toileting assistance or prompting (OHTAC, 2008). Nurse-led interventions for continence care, like T2DM care, are delivered using a self-management education and support approach. As well, self-management support and treatment for T2DM and UI could be managed synergistically, where treatment for one (glycemic control) could improve the other (urge incontinence) (Boyd & Fortin, 2010; Brown et al., 2005).

Nurse-led treatment of UI has been shown to: (a) reduce UI, (b) improve quality of life, (c) reduce personal costs of disposable incontinence products and laundry, and (d) reduce health-care system costs associated with physician consultation (Bliss et al., 2013; Moore et al., 2003; Northwood & Skelly, 2013; Williams et al., 2005). However, continence care interventions do not typically include strategies to manage T2DM. Moreover, the applicability of evidence-based continence interventions to older adults with T2DM is undetermined (Dumoulin et al., 2017; RNAO, 2011). Further, other than acknowledgment of the impact of single diseases on UI, these guidelines do not address how to manage UI within the context of MCC nor do they consider the impact of the social determinants of health on the management of UI. Thus, it is not known how older

adults experience living with both T2DM and UI nor how nurses intervene to support these older adults in their homes.

Home-Care Services for Older Adults with Diabetes and Urinary Incontinence

Over 1.8 million Canadians receive publicly funded home-care services and 70% of home-care clients are older adults (Better Home Care in Canada Partners, 2016). In Ontario, the Ministry of Health and Long-term Care (MOHLTC) is the steward of home care and provides legislation, policy, and funding as well as compliance-monitoring to this sector (CHCA, 2013). Home care is locally organized by 14 LHINs (prior to legislative changes in May 2017, home care was coordinated by Community Care Access Centres) that are responsible for planning and funding home care (Ontario MOHLTC, 2016).

Care-coordinators who are employed by the LHINs determine client eligibility for services and coordinate care. Services, such as nursing, personal support, occupational therapy, physical therapy, nutrition, and social work, are provided by numerous service provider agencies (approximately 260) across the province that are locally contracted by the LHINs (Donner et al., 2016). Nurse continence advisors are specialty nurses employed by some home-care agencies in the province and can be contracted by the LHIN care coordinator. However, there are not enough nurse continence advisors in Ontario, which means not every LHIN has access to this specialty resource (OHTAC, 2008). Community support service agencies also provide non-clinical services to older adults, such as meals, transportation, and caregiver support (CHCA, 2013; Donner et al., 2016).

The main challenge identified within the home-care sector is the impact of an aging population on the demand for and complexity of home-care service provision (Better Home Care in Canada Partners, 2016). Many of these older adult clients with complex needs have T2DM and UI. The majority of Canadian older adults want to age-in-place, living in their own homes as long as possible (CIHI, 2011; Donner et al., 2016). Over the next 20 years, the older adult population (≥ 75 years) is expected to double in size, placing increased demands on home care and the larger health-care system (CIHI, 2017).

The complexity of the care required in the home setting continues to increase. For example, 73.5% of clients (of all ages) served by Ontario LHINs had high care needs in 2015/2016 compared to only 37.4% in 2009/2010 (Ontario Association of Community Care Access Centres [OACCAC], 2016). The classification of high care needs is based on the standardized assessment completed on all long-stay home-care clients—the RAI-HC (Morris et al., 2012). High care needs are due to MCC and periods of unstable health that require frequent interactions with various health, social, and community care providers (OACCAC, 2016). The complex needs of community-dwelling older adults has also strained long-term care home resources and intensified the demand for home-care services (CIHI, 2017).

The home- and community-care setting has been a focus of national and provincial government policy and funding initiatives over the past fifteen years (Baranek, Deber, & Williams, 2004; Donner et al., 2015; Ontario MOHLTC, 2015, 2019; Sinha, 2013). Ontario is in a period of tremendous change and uncertainty as the government

begins the process of reorganizing home and community care, primary care, hospitals, palliative care, residential long-term care, and mental health and addictions services into “Ontario Health Teams.” These teams will be responsible for delivering and coordinating the care of an entire population within a defined geographic area (Ontario MOHLTC, 2019). This process will include the transition of the existing LHINs into the new Ontario Health Teams (Ontario MOHLTC, 2019).

Investigations of the current home-care system have consistently called for improvements in home-care delivery for older adults, including addressing funding and service shortages (Better Home Care in Canada Partners, 2016; Donner et al., 2015; Markle-Reid et al., 2017; Sinha, 2013). An improved home-care system includes utilization of highly skilled home-care nurses to deliver and coordinate this complex care (Markle-Reid et al., 2017; Ontario Home Care Association [OHCA], 2011). Other recommendations for changes to the home- and community-care setting have included ensuring (a) patient and family-centred care, (b) accessible and equitable care, (c) integrated care that reflects the unique needs of local communities, (d) accountable and consistent care, (e) sustainable care, and (f) enhanced use of technology to improve coordination and reduce duplication (Better Home Care in Canada Partners, 2016; Markle-Reid et al., 2017; Ontario MOHLTC, 2016; 2019). The enactment of these recommendations for change will require significant and continued advocacy from nurses and professional nursing organizations partnering with health- and home-care organizations (RNAO, 2016).

In addition to older adults' preference to age-in-place, these recommendations for change are related to fiscal concerns over the high costs to government of providing care to older adults in the acute and long-term care environments (Baranek, Deber, & Williams, 2004; Donner et al., 2015; Ontario MOHLTC, 2015). The MOHLTC, in an effort to contain the rising public costs of health care, has intentionally shifted care that previously would have required hospitalization—such as intravenous therapy with infusion pumps—to the home environment (CHCA, 2013). The cost of home care is considerably less than acute or long-term care services, with the average per diem cost to treat an older adult in the hospital environment being \$842 compared to \$126 in long-term care and \$42 in the home (CHCA, 2013; Home Care Ontario, 2011). Despite the increasing demand for home-care services and the increasing complexity of home-care clients, the proportion of nursing services as a percentage of total home-care services in Ontario is declining, from 25% in 2003/4 to 21% in 2009/10 (OHCA, 2011).

Given the home-care setting has become a priority focus for health-care system reform and redesign, nurses and nursing researchers will play pivotal roles in shaping this process (Ontario MOHLTC, 2019). The clinical and system complexity inherent in living with T2DM and UI while receiving home-care services requires careful study and examination to gain an improved understanding from both older adults' and home-care nurses' perspectives, which is important to inform care approaches for this group of older adults that considers their experiences and prevents the associated negative health outcomes.

Personal Statement of Disciplinary Orientation and Assumptions

My motivation and enthusiasm for studying this topic is related to the clinical challenges I have experienced as an advanced-practice nurse continence advisor supporting clients with T2DM—first, in an outpatient nurse-led clinic, and presently, in home care—to achieve continence. For numerous older adults I have met, the most significant contributing factor to their UI has been T2DM. I have encountered many instances of sub-optimal T2DM control or under-treatment of T2DM in older adults that has prevented achieving my clients' goals of improvement of incontinence or urinary symptoms. I have struggled to coordinate T2DM care in the home with clients' circles of care that span multiple settings, sectors, and providers. My goal is that this research will be foundational to the development and evaluation of a nurse-led strategy to promote continence and manage T2DM in the home-care setting.

As an advanced practice nurse, I practice person- and family-centred care. As such, my practice is informed by the unique needs and desires of each of my clients, as well as by biomedical and nursing evidence and the social determinants of health. In preparation for this thesis, I proposed a tentative definition of multimorbidity consistent with this position based on an integrative review of the literature:

Multimorbidity takes place in a socioeconomic and political context that enables or disables access to health care and has an impact on health and well-being. Multimorbidity in older adults is the combination of chronic conditions, including both mental and physical conditions. Multimorbidity can create vulnerabilities to life satisfaction, function, mortality, and independence depending on the level of disability and frailty and the presence of social support. The structural determinants of health in older adults with multimorbidity include education, gender and income. The ideal processes of care for older adults with

multimorbidity include the key foci of patient- and family-centred care, care coordination (including across transition points), interpersonal continuity and provision of care in context (i.e., home environment). Health care for persons with MM should be provided in a relationship centred on the individual's goals and context. (Northwood, Ploeg, Markle-Reid, & Sherifali, 2017, p. 12)

My disciplinary orientation as a nurse extends philosophically into my approach to research: that its purpose must be grounded in practice and human problems and its outputs must be relevant to nursing and interprofessional practice (Thorne, 2016). Furthermore, I believe that knowledge is co-created, consistent with a constructivist world view, and should account for human commonalities and differences (Thorne, 2016). I reject the ageist notion that older adults are a homogenous group and through my practice, research, and writing, I seek to dispel that myth. I do not view clinical dilemmas solely at the level of the person or the clinician, but rather utilize a model of complexity that enables comprehensive practice and research activities attuned to the social determinants of health and the economic, political, and social context (Grembowski et al., 2014; Solar & Irwin, 2010).

Thesis Content

This thesis has been prepared as a sandwich thesis with eight chapters. Four of the chapters are manuscripts that have been prepared for publication. Chapter 3 (study protocol) has been published and Chapters 4, 5, and 6 (study results) have been submitted for publication.

Chapter 1 lays the foundation for the need for this research with the discussion of the background and context, purpose and overall research process, research questions,

and disciplinary orientation. Chapter 2 is a literature review describing the current state of knowledge regarding older adults with T2DM and UI receiving home care from both quantitative and qualitative perspectives. Chapter 3 is a published, peer-reviewed paper detailing the methodological protocol for the thesis (Northwood, Ploeg, Markle-Reid, & Sherifali, 2019).

Chapters 4, 5, and 6 are manuscripts describing the results in the quantitative and qualitative strands of the mixed methods research thesis. Chapter 4 is a manuscript describing the prevalence and correlates of UI in older adults with T2DM receiving home care in Ontario, Canada. Chapter 5 is a manuscript sharing the thematic results regarding older adults' experiences living with T2DM and UI while receiving home care. Chapter 6 is a qualitative manuscript reflecting the experiences of the home-care nurse participants in providing care to older adults with T2DM and UI.

Chapter 7 details the mixed methods analysis and integrates the quantitative and qualitative strands of the thesis into a mixed methods interpretation. Chapter 8 is the concluding, discussion chapter, which summarizes the thesis findings and provides implications generated from the findings for practice, education, policy, and research.

Across Chapters 3, 4, 5, and 6 there is some necessary overlap of content. Specifically: (a) introductions to the rationale for the need for the study and background regarding older adults with T2DM and UI receiving home care; (b) description of the study design, conceptual framework, methodology, and methods; and (c) ethical

considerations. Additionally, each of these findings chapters also contain implications, strengths, and limitations, which are also considered in Chapter 8.

The manuscripts presented in Chapters 3 through 6 are co-authored. The student, Melissa Northwood, is the first author, and contributed to the conception and design of the study, the acquisition of the quantitative data and the collection of interviews, the analysis of both qualitative and quantitative data, and the writing and revising of each chapter and manuscript. Dr. Jenny Ploeg, the student's supervisor, contributed to the conception and design of the study, participated in the qualitative analysis process, reviewed the quantitative analysis, and revised the chapters and manuscripts critically. The two supervisory committee members, Drs. Maureen Markle-Reid and Diana Sherifali, contributed to the conception and design of the study, reviewed the analysis, and critically revised the chapters and manuscripts. Dr. Kathryn Fisher reviewed the quantitative analysis and critically revised the manuscript presented in Chapter 4.

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CHAPTER TWO

Literature Review

Introduction

A literature review was conducted to understand the nature of living with type 2 diabetes mellitus (T2DM) and urinary incontinence (UI) for older adults (≥ 65 years) receiving home-care services. The questions guiding the literature review were:

1. What are the prevalence and correlates of UI in community-dwelling older adults with T2DM?
2. What are the experiences of community-dwelling older adults with T2DM and UI receiving home-care services?
3. What are home-care nurses' experiences caring for older adults with T2DM and UI?

The literature search was updated and refined several times during the study: (a) at the outset to determine the need for the investigation; (b) during the quantitative and qualitative analysis to explore emerging findings; (c) in the preparation of each manuscript to contrast findings with existing literature, including studies published after the initial literature search; and (d) during the mixed methods interpretation in order to locate the implications in current evidence. Characteristics of included literature are presented at the end of this chapter.

Search Strategy and Methods

Three separate literature searches were undertaken to address the research questions guiding the literature review. Each of the three searches were conducted in MEDLINE and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and limited to English language, participants aged ≥ 65 years, and publication years 2000 to 2019 (to capture earlier research on the qualitative experience of living with UI yet not too remote given the ever changing context of health-care delivery). A health sciences librarian was consulted regarding the development of the search strategies (see Table 1 for the topic areas and corresponding subject headings and keywords used in the three searches). Subject headings and keywords were linked with the operator, “OR.” Then the topic areas were linked with the operator “AND” for each of the three main literature searches conducted.

The aim of the first literature search was to address question 1: What are the prevalence and correlates of UI in community-dwelling older adults with T2DM? Studies were included in this review if they met the following criteria: (a) focused on older adults (aged ≥ 65 years); (b) included only community-dwelling, non-institutionalized older adults receiving home care; and (c) explored the prevalence and correlates of UI in older adults with diabetes using any quantitative study design. Studies were excluded if they were: (a) study protocols, conference abstracts, unpublished dissertations, or commentaries; or (b) secondary publications from a primary study.

The aim of the second literature search was to explore question 2: What are the experiences of community-dwelling older adults with T2DM and UI receiving home-care

services? No studies were found on the experiences of living with both T2DM and UI for older adults receiving home care. As a result, the literature review was revised to focus on the experience of living with T2DM, UI, or MCC. To capture relevant research evidence, experiences were defined broadly for this search, including any aspect of living with T2DM, UI, or MCC, such as receiving health care or self-managing. Therefore, studies were included if they met the following criteria: (a) focused on older adults (aged ≥ 65 years); (b) included only community-dwelling, non-institutionalized older adults; (c) explored qualitatively older adults' experiences living with T2DM, UI, or MCC; and (d) included older adults receiving home care. Studies were excluded if they were: (a) focused on the experience of living with causes of incontinence (such as, prostate cancer or creation of neo-bladder); (b) study protocols, conference abstracts, unpublished dissertations, or commentaries; or (c) secondary publications from a primary study.

The aim of the third literature search was to explore question 3: What are the experiences of home-care nurses caring for older adults with T2DM and UI? No studies were found on home care nurses' experiences caring for older adults with both T2DM and UI. As a result, literature was revised to focus on nurses' experience caring for clients with T2DM and caring for older adults with UI. Again, experiences were defined broadly to ensure relevant research was captured in the review and included how home-care nurses care for older adults with T2DM or UI as well as specific aspects of care, such as wound care. Studies were included if they met the following criteria: (a) focused on home-care nurses; (b) related to community-dwelling older adults (aged ≥ 65 years) receiving home care; and (c) explored home-care nurses' experiences caring for older

adults with T2DM and UI using any qualitative study design. Studies were excluded if they were: (a) focused on nurses in other sectors, such as long-term care; (b) study protocols, conference abstracts, unpublished dissertations, or commentaries; or (c) secondary publications from a primary study.

Quality Assessment

The quantitative research was critically appraised using the Joanna Briggs Institute Checklist for Analytical Cross-Sectional Studies (Joanna Briggs Institute, 2016). The purpose of the checklist is to assist in “assessing the trustworthiness, relevance and results of published papers” (Joanna Briggs Institute, 2016). The qualitative research was appraised using the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (CASP, 2018). This checklist is designed to facilitate systematic consideration of whether a qualitative study has valid results and if the results contribute to current knowledge (CASP, 2018). These two checklists were chosen for the critical appraisal process as they are practical to use, comprehensive, and commonly used in nursing research. Research studies were not included in the review based on the quality appraisal process but rather the quality of the research was considered in the determination of gaps in the body of knowledge regarding older adults living with and managing T2DM and UI while receiving home-care services.

Results

Prevalence and Correlates of Urinary Incontinence in Older Adults with Diabetes

Two studies were identified on the prevalence of UI in older adults with T2DM receiving home care and one of these studies also examined the correlates, as shown in

Table 4 (Hsu et al., 2014; Vetrano et al., 2016). Both studies used a cross-sectional design and included older adult home-care recipients from the United States (Hsu et al., 2014) and Canada and Europe (Vetrano et al., 2016). The purpose of the study by Hsu and colleagues (2014) was to determine risk factors for UI in older adults with diabetes (type not specified) receiving home care. The second study sought to determine the association between different diseases, including diabetes, with geriatric syndromes—UI being one—in older home-care clients (Vetrano et al., 2016).

Prevalence of urinary incontinence among older adults with diabetes. Hsu and colleagues (2014) noted a 44% prevalence rate of UI in their cross-sectional study of older adults receiving home-care services. This included participants who were seldom incontinent (<1 time per week) and often incontinent (>1 time per week). Vetrano et al. (2016) noted incontinence (any frequency of urine loss from < daily to multiple times daily) in 48% of older adults with diabetes. These two studies were appraised to be of high methodological quality as they provided enough detail and appropriate approaches for the domains assessed (see Table 2; Joanna Briggs Institute, 2016).

Correlates of urinary incontinence among older adults with diabetes. Only one study examined the correlates associated with UI among older persons with diabetes receiving home-care services (Hsu et al., 2014). The factors examined in this study were: demographic (gender, age, race/ethnicity), geriatric (dependence in ambulation, dependence for transferring, cognitive impairment), diabetic (use of glucose-lowering medication, hemoglobin A1C levels), diabetes-related complications (peripheral vascular

disease and renal, ophthalmologic, and neurological complications), depressive symptoms, and diuretic use (Hsu et al., 2014).

Hsu et al. (2014) found the demographic factors associated with UI included 85 years of age and older (odds ratio [OR] 3.13, 95% confidence interval [CI]: 2.15, 4.56), African American race (OR 2.12, 95% CI: 1.14, 3.93; reference Asian), and White race (OR 2.15, 95% CI: 1.28, 3.59; reference Asian). Geriatric factors associated with UI in this study were dependence on another for transferring (OR 2.02, 95% CI: 1.58, 2.58) and walking (OR 1.49, 95% CI: 1.19, 1.84), and cognitive impairment (OR 1.41, 95% CI: 1.15, 1.73: Hsu et al., 2014). Diabetes-related factors associated with UI included use of insulin (OR 2.62, 95% CI: 1.67, 4.13) and glucose-lowering oral medications (OR 1.81, 95% CI: 1.33, 2.45: Hsu et al., 2014). UI was not associated with female sex, diabetes complications, depressive symptoms, or diuretic use (Hsu et al., 2014).

Experiences of Older Adults Living with Diabetes and Urinary Incontinence

Eight studies were located that explored the experiences of community-dwelling older adults living with diabetes and only one study included some participants who were receiving home care. Four studies were reviewed that explored the experiences of older adults living with UI and some of the participants in two of the studies were receiving home care. Six studies were found regarding the experience of living with MCC and this literature is summarized in the next chapter (see Chapter 3, Supplemental Table 1; Backman et al., 2018; Eckerblad et al., 2015; Gill et al., 2014; Jarling et al., 2018; Newbould et al., 2012; Ploeg et al., 2017) while the quality appraisal results are in this chapter's Table 3.

Experiences of older adults living with diabetes. The eight studies identified on the experiences of older adults living with diabetes are summarized in Table 5 (Brewer-Lowry, Arcury, Bell, & Quandt, 2010; Carolan-Olah & Cassar, 2018; Huang, Gorawara-Bhat, & Chin 2005; Joo & Lee, 2016; Song, Lee, & Shim, 2009; Washington & Wang-Letzkus, 2009; Woodcock & Gillian, 2013; Wilson, 2012). Most of the studies employed a qualitative descriptive design (Brewer-Lowry et al., 2010; Carolan-Olah & Cassar, 2018; Joo & Lee, 2016; Washington & Wang-Letzkus, 2009), one used grounded theory (Huang et al., 2005), and three studies did not explicitly discuss the study design (Song et al., 2009; Woodcock & Gillian, 2013; Wilson, 2012).

Across the studies, there were approximately equal male and female participants, of diverse ethnicities (Italian Australian, African American, Chinese American, Korean American, Korean, Caucasian), and living in rural and urban settings. Only one study mentioned the inclusion of participants receiving home care (Brewer-Lowry et al., 2010). Some studies included participants with both type 1 and 2 diabetes (Brewer-Lowry et al., 2010; Song et al., 2009; Wilson, 2012). The research was conducted in the United States (Brewer-Lowry et al., 2010; Huang et al., 2005; Joo & Lee, 2016; Washington & Wang-Letzkus, 2009), the United Kingdom (Woodcock & Gillian, 2013; Wilson, 2012), Australia (Carolan-Olah & Cassar, 2018), and Korea (Song et al., 2009). Five studies focused on exploring diabetes self-management practices in older adults (Brewer-Lowry et al., 2010; Huang et al., 2004) and in different cultural groups (Chinese, Korean, Korean American: Joo & Lee, 2016; Song et al., 2009; Washington & Wang-Letzkus, 2009). Three studies sought to understand older adults' experiences receiving health care

services for their diabetes (Carolan-Olah & Cassar, 2018; Woodcock & Gillian, 2013; Wilson, 2012).

Support with self-management activities—such as meal preparation, medication delivery, capillary glucose monitoring, and exercise—were seen as very helpful by participants (Brewer-Lowry et al., 2010; Joo & Lee, 2016; Song et al., 2009; Washington & Wang-Letzkus, 2009). This support was provided by home health aides, family, friends, and social clubs (Brewer-Lowry et al., 2010; Carolan-Olah & Cassar, 2018; Joo & Lee, 2016; Song et al., 2009; Washington & Wang-Letzkus, 2009). Some participants performed self-management activities while staying positive, remaining optimistic, and drawing strength from their religious faith (Carolan-Olah & Cassar, 2018; Washington & Wang-Letzkus, 2009).

Across the studies, the results also suggested that self-management activities—such as weight loss and diet modifications—were not easy for participants and some described feeling guilty and fearful of experiencing a poor health outcome (Carolan-Olah & Cassar, 2018; Woodcock & Gillan, 2013). Barriers to enacting self-management activities included feeling unwell (e.g., pain, fatigue), forgetting to take medications, and having no time for self-management due to caregiving responsibilities to a spouse or grandchildren (Carolan-Olah & Cassar, 2018; Joo & Lee, 2016; Song et al., 2009). Additionally, participants described financial costs to living with diabetes, including transportation to frequent physician visits, diabetes medications, insurance, food, and heating (Joo & Lee, 2016; Wilson, 2012).

The three studies that explored older adults' experiences interacting with health-care providers reported that participants wanted to be treated as persons (Wilson, 2012). Participants in a number of studies valued being supported by providers who were knowledgeable about diabetes, provided information in their first language or through a translator, and helped them achieve goals that were important to them, such as maintaining independence (Huang et al., 2005; Joo & Lee, 2016; Woodcock & Gillan, 2013; Wilson, 2012).

The included studies were not of high methodological quality, particularly given that many did not state the use of a methodology to rigorously structure the investigations (see Table 3; CASP, 2018). Additionally, most of the studies did not report consideration of the relationship between the researcher and the participants, how ethical standards were maintained, or detailed analytical procedures (CASP, 2018).

Experiences of older adults living with urinary incontinence. Only four studies were identified that explored the experiences of older adults with UI (see Table 6; Andersson, Johansson, Nilsson, & Sahlberg-Blom, 2008; Horrocks, Somerset, Stoddart, & Peters, 2004; Park, Yeoum, Kim, & Kwon, 2017; White et al., 2014). Three of these studies used a qualitative description design (Horrocks et al., 2004; Park et al., 2017; White et al., 2014), and one used phenomenology (Andersson et al. (2008).

The majority of the participants in these studies were women. A subset of the sample in two of these studies were receiving home care (Andersson et al., 2008; Horrocks et al., 2004). The studies were conducted in Sweden (Andersson et al., 2008),

England (Horrocks et al., 2004), Korea (Park et al., 2017), and Australia (White et al., 2014). Each study explored some aspect of the experience of living with UI. Specifically, Andersson et al. (2008) sought to describe the experiences of those who did not desire further treatment for UI, while Horrocks et al. (2004) wanted to understand why older adults did not access available continence services. One study explored UI in persons who had survived a stroke (White et al., 2014) and another sought to explore self-management experiences of Korean older women with UI (Park et al., 2004).

Several cross-cutting themes were identified across the studies. First, participants regarded UI as a normal part of aging despite finding it unpleasant and bothersome (Andersson et al., 2008; Horrocks et al., 2004; Park et al., 2017). The Korean women in the study by Park et al. (2017) also attributed UI to emotional stress. These beliefs contributed to not disclosing UI to health-care providers. However, some participants noted that they were not asked about UI by home-care nurses or during hospitalization post-stroke (Horrocks et al., 2004; White et al., 2014). Some of the included participant quotes suggested that patients felt that asking health-care providers about UI was not as high of a priority compared to seeking advice about other chronic conditions, such as arthritis or the after effects of a stroke (Andersson et al., 2008; White et al., 2014). For example, a participant in one study found getting out to the doctor so challenging that she would only address the most serious issues, such as refilling her prescriptions (Andersson et al., 2008). In contrast, many of the participants in the study by Park et al. (2017) had received treatments for UI (e.g., surgery, medications) but this had not resolved UI.

Subsequently, participants managed UI with several self-initiated strategies. Participants employed strategies that were positive, such as knowing the location of public toilets when out, using incontinence products, wearing dark clothing, performing pelvic floor muscle exercises, and walking (Andersson et al., 2008; Park et al., 2017; White et al., 2014). Unfortunately, participants also used potentially harmful strategies, such as restricting fluids, voiding frequently, and making homemade pads (Andersson et al., 2008; Horrocks et al., 2004; Park et al., 2017; White et al., 2014). Perhaps most potentially harmful was participants' withdrawal from social activities due to embarrassment, shame, and fear of odour or public accidents (Horrocks et al., 2004; Park et al., 2017; White et al., 2014).

This qualitative literature on the experience of living with UI was of moderate quality overall (see Table 3). Methodological limitations included a lack of: (a) justification of study design choice, (b) description of ethical provisions, (c) explanation of analysis, and (d) declaration of the relationship of researcher to participants (CASP, 2018).

Experiences of Home-Care Nurses Caring for Older Adults with Diabetes and Urinary Incontinence

Three studies were found that described the experiences of home-care nurses caring for older adults living with diabetes and only one regarding their experiences caring for older adults with UI.

Experiences of home-care nurses caring for older adults with diabetes. Three qualitative studies were identified that explored the experiences of home-care nurses caring for older adults with diabetes (type of diabetes not specified; see Table 7; Fox, Munro, & Brien, 2006; Gifford, Graham, & Davies, 2013; Kolltveit, et al., 2017). One of these studies used ethnography (Fox et al. 2006), and two used a qualitative descriptive design embedded in a randomized control trial of a telemedicine intervention for diabetic foot ulcers (Kolltveit et al., 2017) and a pilot study of a diabetic foot ulcer care guideline in home care (Gifford et al., 2013).

The participants were home-care nurses practicing in Canada (Fox et al., 2006; Gifford et al., 2013) and Norway (Kolltveit et al., 2017). Outpatient specialists, nurse managers, and clinical resource nurses were also participants in two of the studies but the results regarding the home-care nurses were considered in this review (Gifford et al., 2013; Kolltveit et al., 2017). The aim of the study by Fox and colleagues (2006) was to explore the challenges and needs of nurses providing diabetes care in the home setting. Gifford et al. (2013) investigated the barriers to home-care nurses' use of recommendations in a diabetes wound-care guideline (e.g., assessment of glycemic control, wound measurement, foot deformities, and pressure from footwear). The Norwegian study examined how a telemedicine intervention for diabetic foot ulcer care was applied and experienced differently by home and outpatient nurses and what nursing practice implications could be drawn from observations of the enactment of this new intervention (Kolltveit et al., 2017).

The findings from these qualitative studies of home-care nurses' experiences identified nurse, team, client, organization, and system barriers to caring for older adults with diabetes in the home-care setting. At the individual level, nurses had knowledge and skill deficits related to best practices for the management of diabetic foot ulcers and some nurses perceived no reason to change practice (Gifford et al., 2013). Home-care nurse participants worked autonomously and any collaboration—for example, with primary-care physicians or specialist wound teams—was done outside of the home visit (Fox et al., 2006; Gifford et al., 2013; Kolltveit et al., 2017). Nurse participants were frustrated that there was limited access to registered dietitians, social workers, and foot care services, which they felt their clients required in the home setting (Fox et al., 2006). Individual client issues also affected nurses' ability to provide diabetes care, including cognitive impairment, mental health issues, language barriers, elder abuse, poverty, social isolation, food insecurity, and a lack of financial resources for footwear or transportation to specialist appointments (Fox et al., 2006; Gifford et al., 2013; Kolltveit et al., 2017). Nurses were dealing with a number of social, mental, and physical concerns in addition to providing diabetes care. Nurse participants felt that providing diabetes care in the home afforded them the opportunity to observe these types of client issues that impacted both their care and their clients' health (Kolltveit et al., 2017).

Nurse participants also described multiple organization- and system-level barriers to providing in-home diabetes care to older adults. Specifically, in the trial of the new telemedicine intervention for diabetic foot ulcers, home-care nurses did not have access to laptop computers or Wi-Fi access in their clients' homes. Thus, they had to review

their clients' health records ahead of their home visits at their office, remember what they had done and observed in the home visit, and electronically document this at the end of their day (Kolltveit et al., 2017). Additionally, the photos of the ulcers they took to share with the specialist team were often of poor quality due to dim lighting in clients' homes or awkward client positions that did not facilitate capturing the best image (Kolltveit et al., 2017). Other organization- and system-level barriers to providing home diabetes care included: lack of equipment (i.e., wound measuring rulers), inability to access clients' blood work results, limited number of wound- or diabetes-specialty nurses for support, and restricted number of home visits and visit lengths (Fox et al., 2006; Gifford et al., 2013).

The Kolltveit et al. (2017) study was of high methodological quality, likely influenced by the use of a reporting guide to accurately document key methodological processes and decisions (see Table 3). The quality of the other two studies was difficult to appraise due to non-documentation of analytical process, ethical provisions, and the role of the researcher in relationship to the participants (CASP, 2018).

Experiences of home-care nurses caring for older adults with urinary incontinence. Only one study was identified that explored the experiences of home-care nurses caring for older adults with UI (see Table 8; Jansen, McWilliam, Forbes, & Forchuk, 2013). This study used a grounded theory approach to understand the social-interaction process of knowledge translation between home-care providers (nurses, personal support workers, social workers, and physiotherapists), family caregivers, and

home-care clients. There were only three nurse participants, all registered nurses. The study was conducted in rural Saskatchewan, Canada (Jansen et al., 2013).

The social process of knowledge translation among home-care providers, caregivers, and clients was described as “translating knowledge through relating” (Jansen et al., 2013, p. 396). From the nursing perspective, participants described learning from the caregiver and client about how to manage UI. They “developed comfort” by listening, asking directly about UI, and building a relationship with the client and caregiver over time (Jansen et al., 2013, p. 397). Nurse participants “facilitated knowledge exchange” not only by teaching but asking how what they recommended would work for both the client and caregiver (Jansen et al., 2013, p. 399).

The study was of high methodological quality and reported on the relevant details required to appraise a study, with the exception of the relationship between the researcher and the participants (see Table 3; CASP, 2018). However, given that only 3 of the 14 participants were nurses, limited conclusions can be drawn about nurses’ experiences.

Discussion

The literature suggests that 44% to 48% of older adults with T2DM receiving home care services have some level of UI (Hsu et al., 2014; Vetrano et al., 2016). There is however, limited knowledge regarding the correlates of UI in older adults with T2DM receiving home care. For example, Hsu et al. (2014) did not explore social support, community resources, health-care system services, and additional individual characteristics (such as socioeconomic status or chronic conditions) that are known to

influence well-being and health in older adults with MCC (Grembowski et al., 2014). The finding that UI was not correlated with female sex or depressive symptoms contradicted other research with older adults that found such associations, indicating the need for further exploration (Dugan et al., 2000; DuMoulin et al., 2008). Furthermore, the generalizability of the findings of Hsu et al. (2014) to the Canadian home-care context is limited due to the relatively small sample size, inclusion of older participants of mostly Asian ethnicity, and the fact that the home-care services provided were designed specifically to forestall long-term care placement.

No studies were located regarding the experiences of older adults with T2DM and UI receiving home-care services and little is known about the experiences of older adults living with T2DM. Existing studies focused on how older adults undertook self-management, however gaps remain in understanding the entirety of the experience. As only one study (Brewer-Lowry et al., 2010) included some participants receiving home care, it is not clear how the experience of living with diabetes can be influenced by receiving home-care services. Furthermore, it is not known from these studies if the participants were living with other chronic conditions, including UI, and how that affected their experiences of living with T2DM. As well, some findings warrant deeper investigation, such as the negative impacts of caregiver burden and financial means on managing T2DM (Joo & Lee, 2016; Song et al., 2009; Wilson, 2012).

The qualitative literature about older adults' experiences of living with UI provided important insight regarding older adults' view of UI as a normal part of aging, self-initiated strategies to manage UI, and the negative emotional impact of UI. Further

exploration would be valuable in the areas of concern that were discussed by participants. First, given that some participants spoke of not prioritizing UI relative to other chronic conditions, learning how they manage UI in the context of diabetes and other chronic conditions and determining what care would be acceptable to older adults with both UI and diabetes would be key areas to uncover. Second, the common finding of not seeking help for UI would be important to investigate more deeply to understand how to make continence care part of routine care for older adults with diabetes. Third, understanding why the treatments for UI that some participants received were perceived as ineffective requires further attention.

Another major gap in the qualitative literature of the experience of living with UI is related to understanding the experience of UI among older adults receiving home-care services. Although some of the participants in the studies were receiving home-care services, no studies specifically focused on this population. As well, this literature did not include descriptions of the social determinants of health, such as education or income. Across this qualitative literature, older adult participants' experiences were portrayed as universal, possibly obscuring important differences amongst older adults. Furthermore, the studies did not include many male participants, so an understanding of their perspectives is required.

No literature was found about the experiences of home-care nurses caring for older adults with T2DM and UI. The qualitative research about the experiences of home-care nurses caring for older adults with diabetes has provided preliminary insights into the experiences of nurses providing diabetes care in the home environment. While the

nurses acknowledged several client issues that made providing diabetes care challenging, such as cognitive impairment or mental health issues, what is not clear is how they tailored their care to account for these types of issues or the presence of other chronic conditions. Furthermore, none of the studies explored how or if nurses approached continence care for these home-care clients with diabetes. Furthermore, two of the three studies focused solely on nurses' experiences managing foot ulcers related to diabetes.

The qualitative study regarding the experiences of home-care nurses caring for older adults with UI highlighted the importance of reciprocity in translating knowledge regarding UI to clients and their family caregivers in the home-care context (Jansen et al., 2013). Similar to the studies that examined home-care nurses' experiences of caring for older adults with diabetes, this study did not reveal how nurses cared for this population beyond the development of a relationship. The exemplar quotes focused on changing incontinence products and cleansing after an incontinent episode with no mention of continence-promoting information being translated by the nurses (Jansen et al., 2103). It is unclear if the nurses intervened to promote continence, and if so, how they intervened. Therefore, it would be important to learn from home-care nurses what types of continence-promoting interventions they implement with older adults with T2DM.

Conclusion

Further research is needed to identify and understand the complex health-care needs of older adults with T2DM and UI and generate implications for changes in home-care nursing practice and the larger home-care system that could facilitate improved health outcomes for this population. Thus, this present mixed methods research study

addresses these knowledge gaps by examining the issue from a quantitative, qualitative, and mixed methods interpretive lens, identifying the components of complexity that older adults with T2DM and UI and the nurses that care for them experience in the home-care context, and understanding how these components could inform care approaches for this group of older adults.

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Table 1

Subject Headings and Keywords Included in Literature Searches

Topic	Subject Heading and Keyword	Literature Search 1	Literature Search 2	Literature Search 3
Diabetes	Diabetes complications, diabetes mellitus, type 2 diabetes mellitus, diabetic patients, <i>diabetes</i>	√	√	√
Urinary Incontinence	Urinary incontinence; incontinence; stress urinary incontinence, urge urinary incontinence, <i>incontinence</i>	√	√	√
Multiple Chronic Conditions	<i>Multimorbidity, multimorbid*</i>		√	
Home Care	Home care services, home care, home health care, <i>home care, community</i>	√		√
Qualitative Research	Qualitative studies, field studies, qualitative research, multimethod studies, <i>qualitative</i>		√	√
Nursing	Nurses, <i>nurs*</i>			√

Note. Keywords are in italics. √ = indicates topics used in search with operator ‘AND’.

Table 2

Critical Appraisal of Studies in Quantitative Literature Review

Studies / Checklist	Criteria						
Joanna Briggs Checklist for Cross-Sectional Studies	Inclusion criteria	Description subjects and setting	Valid and reliable exposure measurement	Objective, standard measurement criteria	Description confounding factors	Valid and reliable outcome measures	Appropriate statistical analysis
Hsu et al., 2014	Y	Y	Y	Y	Y	Y	Y
Vetrano et al., 2016	Y	Y	Y	Y	Y	Y	Y

Note. CT = cannot tell. N = no. Y = yes.

Table 3

Critical Appraisal of Studies in Qualitative Literature Review

Studies / Checklist	Criteria									
CASP Qualitative Checklist	Clear aim	Appropriate methodology	Appropriate design	Appropriate recruitment	Clear data collection processes	Researcher/participant relationship considered	Ethical issues considered	Rigorous data analysis	Clear statement of findings	Contribution of research discussed
<i>Experiences of older adults living with diabetes</i>										
Brewer-Lowry et al., 2010	Y	Y	Y	Y	CT	N	CT	CT	Y	Y
Carolan-Olah & Cassar, 2018	Y	Y	CT	Y	CT	N	Y	CT	N	Y
Huang, et al., 2005	Y	N	N	Y	Y	Y	CT	CT	CT	Y
Joo & Lee, 2016	Y	Y	Y	Y	Y	CT	Y	Y	Y	Y
Song et al., 2009	Y	CT	CT	Y	CT	Y	Y	CT	CT	Y
Washington & Wang-Letzkus, 2009	Y	Y	Y	Y	Y	Y	Y	CT	N	N
Woodcock & Gillan, 2013	Y	CT	CT	Y	Y	N	CT	N	N	Y
Wilson, 2012	Y	Ct	CT	CT	Y	N	N	CT	N	N
<i>Experiences of older adults living with urinary incontinence</i>										
Andersson et al., 2008	Y	Y	CT	Y	Y	Y	CT	Y	Y	Y
Horrocks et al., 2004	Y	Y	CT	Y	Y	N	Y	CT	Y	Y
Park,et al., 2017	Y	Y	Y	Y	Y	N	CT	Y	CT	Y

Studies / Checklist	Criteria									
CASP Qualitative Checklist	Clear aim	Appropriate methodology	Appropriate design	Appropriate recruitment	Clear data collection processes	Researcher/participant relationship considered	Ethical issues considered	Rigorous data analysis	Clear statement of findings	Contribution of research discussed
White et al., 2014	Y	Y	N	Y	Y	N	CT	Y	Y	Y
Experiences of older adults living with multiple chronic conditions										
Backman et al., 2018	Y	Y	Y	Y	Y	N	CT	Y	Y	Y
Eckerblad et al., 2015	Y	Y	CT	N	Y	N	CT	Y	Y	CT
Gill et al., 2014	Y	Y	Y	CT	Y	N	CT	Y	Y	Y
Jarling et al., 2018	Y	Y	Y	Y	CT	N	Y	Y	Y	Y
Newbould et al., 2012	Y	Y	CT	Y	Y	N	CT	Y	Y	Y
Ploeg et al., 2017	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Experiences of home-care nurses caring for older adults with diabetes										
Fox, et al., 2006	Y	CT	Y	Y	Y	N	CT	N	Y	Y
Gifford, et al., 2013	Y	Y	Y	CT	Y	CT	CT	Y	Y	Y
Kolltveit et al., 2017	Y	Y	Y	CT	Y	Y	Y	Y	Y	Y
Experiences of home-care nurses caring for older adults with urinary incontinence										
Jansen et al., 2013	Y	Y	Y	Y	Y	CT	CT	Y	Y	Y

Note. CT = cannot tell. N = no. Y = yes.

Table 4

Studies Examining the Prevalence and Correlates of Incontinence in Older Adults with Diabetes

Authors and Year	Country	Design	Purpose	Sample	Results
Hsu et al., 2014	USA	Cross-sectional	To characterize risk factors for UI among community-dwelling frail older adults with diabetes (n=447). Seldom incontinent: <1 time/week. Often incontinent: >1 time/week. Never incontinent: continent.	n=447 Men and women ≥75 years Type of diabetes not specified. Sample were participating in trial of home-care program to forestall long-term care placement. Large proportion (65%) of Asian ethnicity.	Prevalence of any degree of UI in older adults with diabetes was 44%. (28% were seldom incontinent; 16% often incontinent). Correlates: older age and African American and White race. Geriatric factors included: dependence on others for ambulation and transferring and being cognitively impaired. Diabetes-related factors included: use of insulin and oral glucose-lowering agents. UI was not associated with: gender, A1C, or depressive symptoms.
Vetrano et al., 2016	Canada and 11 European countries	Cross-sectional	To investigate the potential association of diseases, alone or in combination, on the occurrence of geriatric syndromes in older adults. Incontinent: any amount of urine loss (i.e., multiple daily or weekly), and those with indwelling catheters.	n=6903 Men and women ≥65 years Type of diabetes not specified. Sample was randomly selected from existing home-care recipients in Ontario and Europe.	48% of older adult with diabetes had UI. 25% of sample had diabetes (type not specified).

Note. A1C = hemoglobin A1C level. UI = urinary incontinence.

Table 5

Studies Exploring the Experiences of Older Adults Living with Diabetes

Authors and Year	Country	Design	Purpose	Sample	Results
Brewer-Lowry, Arcury, Bell, & Quandt, 2010	USA	Qualitative strand of mixed methods study	To identify approaches to self-management in older adults whose diabetes is well controlled (A1C<6%) and those whose diabetes is poorly controlled (A1C>8%).	n=48 Men (24) and women (24) ≥65 years Types 1 and 2 diabetes Some receiving home-care services. Rural setting.	More older adults in good glycemic control had HHA support with meals. Those with good glycemic control consistently monitored glucose and knew their targets. HHA also reminded older adults to monitor. HHA also helped with medication reminders, calling pharmacy.
Carolan-Olah & Cassar, 2018	Australia	Descriptive	To evaluate older Italian migrants' experience of diabetes care and factors that contribute to local service use.	n=13 Men (8) and women (5) ≥68 years Type 2 diabetes	Multiple negative impacts from diabetes. Socially: could not eat same food as others at Italian social club, guilty about diet. Physically: fatigue, swelling etc. Psychologically: fear of death, stress. Conversely some participants drew on faith and accepted living with diabetes. Many found it difficult to make diet, exercise change but they tried. Others achieved a balance by eating less, drinking less alcohol, exercising, and staying positive.

Authors and Year	Country	Design	Purpose	Sample	Results
Huang, Gorawara-Bhat, & Chin, 2005	USA	Grounded theory	To examine how older patients define their health-care goals, which factors shape their goals, and extent goals relate to self-care behavior.	n=28 Men (12) and women (16) ≥65 years Type 2 diabetes and one cardiovascular risk factor. Predominantly African American.	Older adults' goals were global rather than biomedical (e.g., maintain independence, remain alive and healthy, avoid extra medications, control weight). Medical advice and social comparison influence goals. Variability in adherence to self-care related to diet and exercise, participants were more consistent with taking medications and monitoring capillary blood glucose.
Joo & Lee, 2016	USA	Descriptive	To explore barriers to and facilitators of type 2 diabetes self-management for older Korean-American immigrants who live in Midwest, USA.	n=23 Men (12) and women (11) ≥65 years Type 2 diabetes and only 1 other chronic condition	Barriers to self-management: high financial costs; language barriers; "loss of self-control" re: diet, weight, exercise; forgetting to take medications; limited access to community health-care resources due to language barrier. Facilitators: use of Korean online resources re: diabetes, friends and family support, and translation.

Authors and Year	Country	Design	Purpose	Sample	Results
Song, Lee, & Shim, 2009	Korea	Not provided	To identify the barriers to and facilitators of self-management “adherence” for Korean older adults with diabetes.	n=24 Men (14) and women (10) ≥65 years Type of diabetes not specified	Barriers to self-management: physical (not exercising due to pain or cold weather), cognitive (forgetting medications), having no time (caregiver to other family members), knowledge deficits (re: diet, foot care, medications). Facilitators: participating in ongoing education in support group, having a structured self-care plan, family support (for meals, reminders).
Washington & Wang-Letzkus, 2009	USA	Descriptive	To explore self-care practices of Chinese-American immigrants with type 2 diabetes.	n=13 Men (7) and women (6) ≥65 years Type 2 diabetes	Self-care practices for diet: traditional diet, shared importance of “watching” diet but not specific details. Exercise: group-based stretching. Medications: not taking regularly, not monitoring capillary blood glucose, using herbal teas and medications. Diabetes had not caused lifestyle changes. Community centre main source of social activity. Participants remained optimistic; did not feel that diabetes was a “serious” disease.

Authors and Year	Country	Design	Purpose	Sample	Results
Woodcock & Gillan, 2013	UK	Not provided	To investigate older adults' views of the care they receive for diabetes.	n=13 Men and women ≥75 years Type 2 diabetes Recently attended education class. Inner city, deprived neighbourhood	Participants differed in how serious they felt diabetes was and their knowledge of potential complications. Participants had forgotten much of education, valued face-to-face education, felt pamphlets were not helpful, felt alone and unsupported by health-care providers after initial diagnosis. Participants wanted to have continuity in primary-care provider and appreciated primary-care nurse consultations.
Wilson, 2012	UK	Not provided	To explore views of older adults with either type 1 or type 2 diabetes about the care they received from health-care providers.	n=25 Men (12) and women (13) Types 1 and 2 diabetes	Participants shared that expenses were not recognized by health-care providers: gas to travel to appointments, medications, food, enhanced heating (feel cold from poor circulation). Participants wanted to be treated as individuals not a "disease." Frustrated by receiving differing advice on frequency/need for capillary blood glucose monitoring. Concerned not all health-care providers had correct knowledge regarding diabetes.

Note. A1C = hemoglobin A1C level. HHA = home health aide. Not provided = authors did not specify a particular qualitative methodology.

Table 6

Studies Exploring the Experiences of Older Adults Living with Urinary Incontinence

Authors and Year	Country	Design	Purpose	Sample	Results
Andersson et al., 2008	Sweden	Phenomenology	To describe experiences of living with urinary incontinence among persons who do not desire further assessment or treatment.	n=11 Women ≥66 years 9/11 were receiving home-care services.	Incontinence was experienced as a normal and expected complaint attributed to aging and childbirth. Found incontinence unpleasant and annoying. Over time, participants had found ways to manage the problem of incontinence (frequent voiding, knowing location of toilets when out, product use, etc.). Other chronic conditions took precedence in seeking out medical treatment.
Horrocks et al., 2004	England	Descriptive	To explore the reasons why older adults do not access community continence services.	n=20 Men (9) and women (11) ≥66 years Some received home care services. Deprived, urban area in south-west.	Participants had low expectations regarding health and attributed incontinence to aging. Participants disclosed resignation, shame, embarrassment. Independent management included fluid restriction, frequent voiding, product use. Did not want to bother busy doctor and were not asked by home visiting nurses.
Park, Yeoum, Kim, & Kwon, 2017	South Korea	Descriptive	To explore self-management experiences of Korean women with UI.	n=22 Women ≥65 years	Participants hid UI from family, friends, public as cultural “face-saving.” Main concern of

Authors and Year	Country	Design	Purpose	Sample	Results
					participants was deodorizing perceived smell as were fearful of smell being detected. This led to many strategies (product use, homemade pads, frequent toileting, fluid restrictions, staying at home, knowing location of toilets when out, dark clothing but also pelvic floor muscle exercises and walking). Thought UI was consequence of aging or emotional stress. Many had treatments (surgery, medications, neuromodulation) that did not cure UI.
White et al., 2014	Australia	Descriptive qualitative strand of mixed methods study	To explore the experiences of community-dwelling stroke survivors who were living with UI to understand how the participants' health system context shaped those experiences.	n=8 Men (6) and women (2) ≥69 years Previous admission to hospital with stroke.	Most participants did not receive treatment for UI during hospitalization. Participants' leisure activities and social outings were limited by UI. Self-initiated management included knowing locations of toilets when out, timing length of trips out around voiding, fluid restriction, and product use.

Note. UI = urinary incontinence.

Table 7

Studies Exploring the Experiences of Home-Care Nurses Caring for Clients with Diabetes

Authors and Year	Country	Design	Purpose	Sample	Results
Fox, Munro, & Brien, 2006	Canada	Ethnography	To explore challenges and needs of nurses providing diabetes care in the home setting within an urban community in Ontario, Canada.	n=5 participating in observations of home visits. n=17 participating in focus groups, with 4-22 years' experience in home care. Nurses were from 2 agencies.	Health-care provider as a house guest: nurses took different approaches in home (guest versus taking charge). Participants worked autonomously without a team. Was very difficult to communicate with primary-care physicians. Were frustrated by lack of access to RD, SW, foot care. Limited resources challenged care: limited visit length and number of visits. Had to account for more than diabetes (e.g., cognitive impairment, mental health, language barriers, elder abuse, poverty, social isolation, food insecurity). Nurses wanted to have structured program, like palliative care, to support clients with diabetes and prevent others from developing type 2 diabetes.

Authors and Year	Country	Design	Purpose	Sample	Results
Gifford, Graham, & Davies, 2013	Canada	Descriptive, part of pilot implementation of diabetic foot ulcer care guideline	To understand barriers to home-care nurses' use of 9 guideline recommendations for diabetic foot ulcer care.	n=19 Nurse managers, clinical resource nurse, and home-care nurses	From home-care nurse participants' perspectives, individual barriers: lack of knowledge and skills related to recommendations. Some participants perceived no reason to change practice. Team barriers: poor information exchange with primary-care physician. Organizational barriers: lack of equipment (e.g., wound rulers), inefficient processes, limited number of specialty nurses for support. System barriers: cannot access blood work results. Patient level: participants identified lack of funding for footwear, transportation to specialists.
Kolltveit et al., 2017	Norway	Interpretive description, part of randomized control trial	To investigate how a telemedicine intervention was applied in different practice fields (home-based and outpatient) and what implications might be drawn from observations of its application in diabetic foot ulcer care.	n=7 Home-care nurses (3) and outpatient specialists (4) including certified diabetes educator, wound nurse, podiatrist. Two observations of home visits and interviews.	Implemented a web-based ulcer record augmented by images for wound assessment collected on smart phone for home care, specialist, and primary care collaboration. From the home-care perspective, the environment created challenges: nurses arranged own schedule, looked at electronic health record ahead of home visits, planned for missing equipment, poor lighting, hard to take pictures

Authors and Year	Country	Design	Purpose	Sample	Results
					due to poor lighting and patient positions, documented in electronic health record after visits so had to remember what occurred in home. Working alone in home meant had to try to communicate with specialists after home visit. Participants shared value of seeing person in context to observe mood, food availability, activity, but not always had time.

Note. ER = emergency room. RCT = randomized control trial. RD = registered dietician. SW = social worker.

Table 8

Study Exploring the Experiences of Home-Care Nurses Caring for Older Adults with Urinary Incontinence

Authors and Year	Country	Design	Purpose	Sample	Results
Jansen, McWilliam, Forbes, & Forchuk, 2013	Canada	Grounded theory	To enhance understanding of the social interaction process of knowledge translation between paid care providers (nurses, unregulated care providers), family caregivers, and home-care recipients for in-home management of UI and chronic care.	n=14 care providers HHA (7), nurses (3), SW (2), and PT (2). Rural area	From nurse participants' perspectives, translating knowledge through relating involved: living with the problem (nurses learned from client and caregiver how to manage UI), developing comfort (listening, asking about UI, building relationship), facilitating knowledge exchange (teaching and asking how that would work for client and caregiver). Resulted in co-facilitation of knowledge translation.

Note. HHA = home health aides. PT = physiotherapists. SW = social workers. UI = urinary incontinence.

CHAPTER THREE

TITLE: Understanding the complexity of diabetes and urinary incontinence in older adults receiving home-care services: Protocol for a mixed methods study

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Abstract

Urinary incontinence is a very prevalent problem for older adults with type 2 diabetes mellitus receiving home care services. However, the complexities of living with urinary incontinence and type 2 diabetes mellitus and providing nursing care for older adults in the home care context has received very little research attention. This paper describes a protocol for a convergent, mixed methods research design study to address this knowledge and practice gap. The objectives of the proposed study are to: (a) determine the prevalence and correlates of urinary incontinence in older adults living with type 2 diabetes mellitus receiving home care services; (b) explore the experiences of older adults living with type 2 diabetes mellitus and urinary incontinence receiving home care services; (c) explore the experiences of home care nurses caring for this population; and (d) converge the multiple data sources to provide a deeper understanding of the problem and implications for provision of home care services to this population. The research methods are informed by a model of clinical complexity. The quantitative strand will involve descriptive and inferential analysis of standardized home care assessment data (interRAI) to determine the prevalence and correlates of urinary incontinence in older adults with type 2 diabetes mellitus receiving home care services. Interpretive description methods will be used in the qualitative strand and interviews will be conducted with older adults and home care nurses. The findings will be converged to inform a better understanding of the complexity of living with these chronic conditions for older adults receiving home care services and generate implications for complex

intervention development. This protocol highlights methodological insights in utilizing mixed methods research to inform intervention design.

What is Already Known?

Remarkably very little is known about living with or caring for older adults with type 2 diabetes mellitus and urinary incontinence in the home care sector despite the high prevalence of both chronic conditions in this population. Urinary incontinence and type 2 diabetes mellitus are associated with negative sequelae for older adults, such as impaired function and risk for institutionalization. Research regarding living with multiple chronic conditions is enhanced by employing mixed methods to gain an understanding of all the components affecting clinical complexity.

What This Paper Adds?

This protocol provides a template for other researchers seeking to understand a complex clinical practice problem in a comprehensive manner. As well, the protocol highlights how mixed methods research utilizing a complexity conceptual model and population-level administrative data (interRAI) can enhance the applicability of health research results to the practice world.

Keywords

mixed methods, interpretive description, protocol, older adults, home care, nursing, interRAI

Understanding the complexity of diabetes and urinary incontinence in older adults
receiving home care services: Protocol for a mixed methods study

Introduction

Urinary incontinence (UI) is a common but under-recognized and under-treated complication of type 2 diabetes mellitus (T2DM) for older adults (aged ≥ 65 years) (American Geriatrics Society (AGS), 2013; Brown et al., 2005). While UI would not be considered a life-threatening complication of diabetes, it has a debilitating impact on the health, function, and quality of life of older adults and, consequently, their ability to live independently in the community (Coyne et al., 2013). Diabetes is a global public health burden as older adults with T2DM use more health care resources and the prevalence of T2DM is steadily increasing every year (Canadian Institute for Health Information (CIHI), 2009; International Diabetes Federation, 2013). T2DM affects between 14–23% of older adults and an even greater proportion—25%—of those receiving home care services (Gruneir et al., 2016; Vetrano et al., 2016).

T2DM is associated with an increased risk of complications, including higher mortality, reduced functional status, and increased risk of institutionalization, and for older adults is often accompanied by multiple chronic conditions (MCC) (AGS, 2013; Kirkman et al., 2012; Sherifali & Meneilly, 2016; Vetrano et al., 2016). Notably, a cross-sectional study of older adults with T2DM in Ontario, Canada found that 90% had at least one other chronic condition and 40% had five or more chronic conditions (Gruneir et al., 2016).

Despite the large population of older adults with T2DM receiving home care services, the complexities of managing T2DM with MCC and how to approach diabetes care in this sector has not received significant research attention (Hsu et al., 2014; Sinclair et al., 2012). Furthermore, owing to the lack of recognition of UI and its relationship to T2DM, this aspect of diabetes care has also been under-researched. Thus, this paper will describe a proposed convergent mixed methods research (MMR) design study with the goal of better understanding the complexity of living with T2DM and UI in the context of MCC for older adults receiving home care services.

Background

Very few research studies have examined the relationship between UI and T2DM in older adults and only two cross-sectional studies of older adults with T2DM receiving home care services were located. These studies found UI prevalence rates of 48% in an Ontario and European sample and 44% in the United States (Hsu et al., 2014; Vetrano et al., 2016). In Ontario, UI is a public, reportable, home care quality indicator. The provincial average of home care clients who have newly developed bladder incontinence or whose bladder function has not improved since their previous assessment, increased from 48% in 2009/10 to 60% in 2014/15 (Health Quality Ontario, 2017). Minimal research attention has been paid to the correlates of UI in older adults with T2DM. Hsu et al. (2014) reported that UI was correlated with increasing age, use of insulin, use of oral glucose lowering agents, dependence on ambulation and transferring, and cognitive impairment.

Six qualitative research studies were identified that examined the experience of living with MCC from older adult, caregiver and health care professionals' perspectives (Backman et al., 2018; Eckerblad et al., 2015; Gill et al., 2014; Jarling et al., 2018; Newbould et. al 2012; Ploeg et al., 2017) (refer to Supplementary File 1). These studies included some older adults with T2DM receiving home care services and one study also indicated if participants experienced UI (Eckerblad et al., 2015). Living with MCC was described by participants in these studies as challenging. Associated symptoms, such as pain or fatigue, made it hard for older adults to engage in activities they used to enjoy and perform easily, such as leaving home or exercising (Eckerblad et al., 2015). Some older-adult participants reported feelings of inadequacy and sought “to adjust and endure” (Eckerblad et al., 2015, p. 323) whereas others remained hopeful while accepting the realities of worsening health (Ploeg et al., 2017). Participants were discouraged by becoming dependent on family caregivers or home care supports (Eckerblad et al., 2015) while others emphasized the importance of receiving support from family and friends to remain at home (Ploeg et al., 2017). Participants also described difficulties with managing medications (Gill et al., 2014; Ploeg et al., 2017) and attending appointments with many different specialists (Backman et al., 2018; Ploeg et al., 2017).

Interacting with the health care system was frustrating for older adults because of poor care coordination and challenges following physician treatment recommendations (Backman et al., 2018; Gill et al., 2014; Ploeg et al., 2017). Similarly, both older adult and caregiver participants shared the difficulty of working with health care providers who focus on single diseases rather than taking a holistic approach to health (Ploeg et al.,

2017). Receiving formal home care services required a period of adjustment to both the negative and positive implications (Eckerblad et al., 2015). For example, receiving personal care meant a threat to older adults' privacy and dignity while developing relationships with home care staff afforded opportunities for social engagement (Eckerblad et al., 2015).

Health care professionals found the experience of supporting older adults with MCC “overwhelming, draining and complicated” (Ploeg et al., 2017, p. 7). Health care professionals were frustrated by lack of access to a shared health record, the need to rely on reports from caregivers on outcomes of tests or specialist consultations, and inadequacy of funded services in the home care sector (Gill et al., 2014; Ploeg et al., 2017).

Thus, the complexity of managing UI and T2DM for older adults within the home care context is poorly understood, creating an evidence gap to inform clinical practice. UI is a highly prevalent but clinically under-recognized condition with negative outcomes for older adults with T2DM. The prevalence, correlates, and predictors of UI in this population are poorly understood. Qualitative research is needed to better understand the experiences of older adults living with both T2DM and UI in the context of MCC while receiving home care services as well as the experiences of the home care nurses who care for this population in order to understand what would be helpful, effective, and acceptable care.

Objectives

The overall goal of this proposed study is to better understand the complexity of living with T2DM and UI in the context of MCC for older adults receiving home care services. The specific objectives are as follows: (a) determine the prevalence and correlates of UI in older adults living with T2DM receiving home care services in Ontario, Canada; (b) explore the experiences of older adults living with T2DM and UI receiving home care services; (c) explore the experiences of home care nurses caring for this population; and (d) converge the multiple data sources to provide a deeper understanding of the problem and implications for provision of home care services to this population.

Method

Convergent Mixed Methods Research Design

A convergent MMR design, as articulated by Creswell and Plano Clark (2018), will be employed to answer the overarching, integrated MMR question: What are the components of complexity that older adults with type 2 diabetes mellitus and urinary incontinence and the nurses who care for them experience in the home care context and how could an understanding of these components inform care approaches for this group of older adults? The convergent design involves implementing the quantitative and qualitative strands at the same time in the research process and maintains the separation of the strands until data analysis is complete. The point of interface—where mixing occurs—happens at the interpretation stage when the extent to which the data converge or

diverge to answer the study's MMR question is determined (Creswell & Plano Clark, 2018). Refer to Figure 1 for schematic representation of the MMR design.

The rationale for mixing methods in this study include completeness, context, and diversity of views (Bryman, 2006). First, utilizing both quantitative and qualitative research will provide a comprehensive, complete account of the problem (Bazeley, 2018). Second, the qualitative component will provide the contextual understanding, while the quantitative data will describe the relationship of the dimensions of the problem within that context (Bryman, 2006). Finally, revealing experiences of the older adult and nurse participants through the qualitative strand and the relationship between variables in the quantitative analysis provides a richness through the diversity of views (Bryman, 2006).

Clinical complexity: conceptual model. The challenges of living with MCC creates clinical complexity, which has been conceptualized in a model by Grembowski and colleagues (2014) to guide research in this area. The model was developed from a review of the medical, public health, and epidemiological literature, as well as expert consultation and consensus-building among a MCC research network (Grembowski et al., 2014). The model informed design and decision-making regarding qualitative sampling, selection of quantitative variables, topics for qualitative interview questions, and the joint-display approach for mixed methods analysis (Evans, Coon & Ume, 2011).

This model was chosen to guide the study as it considers the multiple components that could influence health outcomes for older adults receiving home care services (Northwood et al., 2017). Clinical complexity is defined as “the gap between the major

system components: an individual's *needs* and the *capacity* of the health care system to support those needs [emphasis added]" (Grembowski et al., 2014, p. S10). The size and nature of this gap is affected by the main interacting components in the model: the health care system, individual characteristics of the person, social supports, and community resources as well as the economic, health, and social policies that influence health inequalities (Grembowski et al., 2014).

Quantitative strand design. The central research questions for this strand are: Among older adults (aged ≥ 65 years) with T2DM receiving home care services in Ontario, (a) What is the prevalence of UI?; (b) Are there differences in the sociodemographic, psychosocial, functional, and clinical correlates between those with UI and those with no known UI?; and (c) What are the sociodemographic, psychosocial, functional, and clinical predictors associated with UI?

The source of this information will be an administrative, population-level database containing the anonymized, standardized, assessment-tool findings completed on all long-stay (estimated > 60 days) Ontario home care clients, the Resident Assessment Instrument for Home Care (RAI-HC).¹ The RAI-HC is developed and maintained by an international research collaborative—the interRAI (www.interai.org)—and has documented reliability and validity (Foebel et al., 2013; Hirdes, 2006; Hirdes et al., 2008; Landi et al., 2000; Morris et al., 1997, 2012). Assessments with the RAI-HC

¹ Note: The interRAI-HC, an updated assessment tool, replaced the RAI-HC in Ontario in 2018.

done by trained health care professionals is mandated by the Ontario provincial government and many other jurisdictions nationally and internationally (Hirdes, 2006; Morris et al., 2012). A cohort of individuals over age 65 with T2DM receiving home care services over a five-year look-back (2011-2016) will be assembled. In cases where the RAI-HC has been repeated, the most recent data will be included, consistent with other research using this data (Maxwell et al., 2013). Health outcome scales are also embedded within the RAI-HC instrument (refer to Table 1) and these are generated by software-based algorithms that have been validated against gold-standard, clinical-assessment tools (Armstrong, Stolee, Hirdes, & Poss, 2000; Burrows et al., 2000; CIHI, 2013; Hirdes, Frijters, & Teare, 2003; Landi et al., 2000; Martin et al., 2008; Stolee et al., 2009).

Variables in the Resident Assessment Instrument for Home Care. The dependent variable in this study is UI. Continence status is determined in the RAI-HC by a look-back at the previous three days and is graded based on five categories of severity (refer to Table 2) (Morris et al., 2012). For this study, UI will be classified as a dichotomous variable, continent or incontinent. The incontinent variable will include both the frequently incontinent and incontinent categories. The continent variable will include the continent, infrequently incontinent, and occasionally incontinent categories. The rationale for this dichotomy is that older adults experiencing daily episodes of incontinence would have different health care needs than those experiencing occasional urine loss (Dumoulin et al., 2017). The independent variables in this study—clients’ sociodemographic, psychosocial, functional and clinical characteristics and health service utilization—will be assessed using a variety of items and scales in the RAI-HC. These

variables were selected based on components of the complexity model (Grembowski et al., 2014), literature on the correlates and complications of T2DM and UI, and their availability in the RAI-HC (refer to Table 3).

Quantitative strand analysis. IBM SPSS Statistics version 24 will be used for the analysis. Percentages and frequencies will be used to describe the categorical data (e.g., sex) and means will be used to describe the central tendency of the continuous data (e.g., age). Differences between older adults with T2DM and UI and older adults with T2DM but no known UI will be analyzed using inferential statistics: independent *t* tests for continuous variables and the chi-square test of independence for categorical variables. A *p* value < 0.001 will be considered statistically significant. However, given the large sample size typical of working with RAI-HC data, it will not be meaningful to strictly rely on *p* values, thus the effect size and clinical significance of the differences will be considered (Guthrie, Thériault, & Davidson, 2015). Significant associations between each independent variable and the outcome (UI) will be assessed using logistic regression. Independent variables that demonstrate statistical and clinical significance will be included as factors in a multivariate model. Odds ratios (OR) representing at least a 20% clinically relevant difference (i.e., $OR \geq 1.2$) along with effect size ≥ 0.2 will be used to identify potential predictors of UI (Fisher et al., 2014; Guthrie et al., 2015). Multicollinearity will be evaluated before a final model will be established. Goodness-of-fit of the regression models will also be assessed using the *c* statistic (area under the receiver operating characteristic curve) and sensitivity and specificity measures. The goal will be to produce a model that best explains the presence of UI in older adults with

T2DM receiving home care services and would be clinically useful to identify older adults most at risk in order to provide service to address those factors.

Qualitative strand design. Sally Thorne's (2016) interpretive description methodology will be employed in the qualitative strand of the study. The central questions for this strand are: (a) How are T2DM and UI experienced by older adults receiving home care services?; and (b) How do home care nurses care for older adults with T2DM and UI?

Interpretive description is an applied, health-research, qualitative approach that answers questions of clinical practice (Thorne, 2016). Interpretive description studies have the following features: (a) occur in natural settings, (b) focus on experiential knowledge, (c) seek human commonalities as well as differences, (d) attend to context, (e) acknowledge the social element of human experience and multiple realities, and (f) have utility for the practice discipline of nursing and other health care professionals (Thorne, 2016).

Qualitative sample. A purposive sampling approach will be used to recruit 15 to 25 older adult participants (Onwuegbuzie & Leech, 2007). The lower limit of 15 older adults is likely still large enough to discern commonalities and differences and achieve sufficient depth (Thorne, 2016). Ten to 15 community nurses will also be recruited, including both generalists (e.g., home-visiting nurses) and specialists (e.g., nurse continence advisors). The smaller sample size for the nurse participants is because each

nurse would likely have seen many clients with T2DM and UI and could speak from the breadth of their experiences (Malterud, Siersma, & Guassora, 2015; Thorne, 2016).

Older adult participants will meet the following inclusion criteria: (a) ≥ 65 years of age, (b) have T2DM and UI, (c) English speaking, (d) receive home care services, and (e) dwell in the community (private home, lodging home or retirement home).

Participants would be excluded if they: (a) have type 1 diabetes, (b) are younger adults, (c) have previously been or currently are a patient of the first author, or (d) due to cognitive issues may not be competent to consent or participate in the interview. The inclusion criteria for the nurses are: (a) registered nurse (RN) or registered practical nurses (RPN), and (b) have worked in the home care sector for at least 6 months.

Recruitment strategies. Multiple active and passive recruitment techniques will be employed. The study has the endorsement of two regional home care programs (Local Health Integration Networks). Interested home care coordinators and nurse participants will be asked to share informational postcards with their clients who meet the inclusion criteria. The first author will also attend diabetes education meetings and group exercise classes to share information about the study. Finally, the study brochure will be posted in public locations (e.g., seniors' recreation centres, family health teams). The second author will email home care nurses in her professional network to solicit participation.

Qualitative strand data collection. One-on-one interviews with both older adults and nurse participants will be the main mode of data collection and will be conducted by the first author (Thorne, 2016). The interviews will be semi-structured, using pre-

determined questions that are open-ended and flexible but allow for clarification with prompts and follow-up questions (refer to Appendices A and B for the interview guides) (Brinkmann & Kvale, 2015; Doody & Noonan, 2013). The questions for the interview guides were generated for each domain of the complexity framework, based on the gaps identified in the literature review and principles of qualitative interviewing (Thorne, 2016). Demographic information will also be collected at the start of the qualitative interviews. Interviews with older adults will take place in their homes (or by phone if preferred) and interviews with nurses will take place at a location of their choosing, such as their agency office, or by phone.

All interviews will be digitally recorded. A field journal will be kept by the first author, documenting impressions and observations regarding the interviews (Thorne, 2016). A reflexive journal will also be maintained to reflect upon how ideas, theoretical allegiances (i.e., the framing of the study in complexity framework), and the first author's own expert clinical opinion influences the interactions with the participants and the analytical process (Thorne, 2016).

Qualitative strand analysis. NVivo 11 will be used to store and organize the qualitative data. All interviews will be transcribed verbatim by a skilled transcriptionist. Interpretive description analysis is governed by the following overarching principles: (a) data collection and analysis are concurrent and interdependent, (b) data sorting and organizing are components of analysis, (c) analysis involves constant comparative analysis, (d) disciplinary preconceptions are managed prior to and during analysis

through a “reflexive accounting” through journaling, and (e) analysis involves looking for commonalities as well as expressions of variance (Thorne, 2016).

The first phase of analysis is “sorting and organizing” (Thorne, 2016, p. 156). Time will be spent reading over the transcripts, making notes, and listening to the interview recordings (Thorne, 2016). The next phase of analysis is “making sense of pattern” (Thorne, 2016, p. 163). This phase involves moving into some initial coding, using broad-based, generic words to group data, and then bringing together descriptions of the experience that are thematically related (Thorne, 2016). The relationships of the themes will be examined to determine if components of one grouping might have a relationship to another group of data or even if the themes could be reorganized to see if new insights are revealed (Thorne, 2016). The first and second authors will undertake these analysis phases by comparing, contrasting, and coming to consensus on the initial structure of the pattern.

The next phase is “transforming pattern in findings” (Thorne, 2016, p. 173). This process will involve testing the relationships between the parts (themes) and the whole (emerging conclusions) (Thorne, 2016). This phase will be undertaken by the first author, including reflection, refinement, and confirmation of conclusions to ensure there is not another explanation (Thorne, 2016). At this stage, the data will be examined to see how it is relating to the complexity model’s components and relationships (Bazeley, 2018; Thorne, 2016). Engagement in analysis with all authors during this phase will allow for critiques and counter-checks (Thorne, 2016). Based on this input and research team

negotiation, the final product of analysis will be produced: a written conceptualization of the findings (Thorne, 2016).

Mixed methods analysis and interpretation. The findings from the analyses of the quantitative and qualitative strands will be compared to generate the mixed methods interpretation (Creswell & Plano Clark, 2018). The complexity model components, the findings from the quantitative analysis, and the qualitative themes will be compared in a “joint display” (refer to Table 4) (Bazeley, 2018; Creswell & Plano Clark, 2018; Moffatt, White, Mackintosh, & Howel, 2006). The joint display table brings together the quantitative and qualitative results for consideration to achieve the MMR goal of integrating the findings (Evans et al., 2011; Woolley, 2009). The results may not match neatly in the joint display but an exploration of the differences or divergence—for example between nurses’ and older adults’ perspectives—is an opportunity to enrich the analysis and lead to further insights (O’Cathain, Murphy, & Nicholl, 2007). Findings that do not align with the complexity model will be described and could have potential to inform future model refinement, as the authors had intended MCC researchers apply the model (Grembowski et al., 2014). Also, the mixed methods interpretation will inform the generation of implications for the provision of home care services to this population (Bazeley, 2018).

Provisions for validation. This convergent MMR design has many provisions for the validity of the quantitative data, the credibility of the qualitative data, and the overall quality validation of the MMR study. For a MMR study, the rigour of the study is

reflected by the provisions made in each strand and overall in the MMR analysis (Creswell, Klassen, Plano Clark, & Clegg Smith, 2010).

Quantitative strand validity. As described earlier, the RAI-HC is a reliable and valid, standardized assessment tool and is completed by trained assessors (Morris et al., 2012). The RAI-HC provides population-level data on all home care recipients so the sample size will be very large. The results will also have external validity as they will apply to the home care population locally as well as in other jurisdictions that have publicly funded home care (Creswell & Plano Clark, 2018; Guthrie et al., 2015). However, the cross-sectional design will only permit assessment of correlations between UI in older adults with T2DM and other variables, not causation.

Qualitative strand credibility. Credibility of the qualitative strand will be ensured by attending to the four principles used to evaluate a study's credibility, according to Thorne (2016): (a) epistemological integrity, (b) representative credibility, (c) analytic logic, and (d) interpretive authority.

Epistemological integrity will be evidenced by demonstration of the first author's self-understanding of her epistemological position in the study and that all decisions made along the qualitative strand of the study remain aligned with that position (Thorne, 2016). This evidence will be documented in a personal statement of disciplinary position, congruent to the underpinnings of the study's conceptual model. Representative credibility will be achieved by having triangulation of data sources: older adults and the clinical insights from the nurses who provide care in the home setting (Thorne, 2016). The clear description of the sample population, sampling strategy, and large sample size

also strengthens the credibility of the qualitative strand (Robinson, 2014). The analytic logic of the study will be evidenced in the carefully documented audit trail. This audit trail will include the steps and decisions made throughout the data collection and analysis that another researcher could theoretically follow, including clearly described coding procedures and expert critiques by research team members (Krefting, 1991; Thorne, 2016). This audit trail will also inform the interpretive authority of the findings as the reader will be able to see how conclusions were formed (Morse, 2018; Thorne, 2016). Furthermore, the act of reflexive journaling coupled with the expert critique by research team members will assure the user of the research that the first author's angle of vision was not over-inscribed on the findings (Morse, 2018; Thorne, 2016).

Quality validation of the mixed methods research study. The overall MMR validity will be based on the study's adherence to the components of a MMR validation framework including design quality, legitimation, and interpretive rigour (Dellinger & Leech, 2007). As described earlier, the convergent MMR design is the appropriate design to answer the study questions and achieve the goals of completeness, contextual understanding, diversity of views, and complementarity (Dellinger & Leech, 2007). Having a clearly documented protocol will ensure that all methods are implemented true to the design, ensuring both design fidelity and analytical adequacy (Dellinger & Leech, 2007). Provisions for legitimation include having an adequate sample size in both strands and a clear analysis plan (Bryman, 2006; Dellinger & Leech, 2007). Interpretive rigour will be attained with: clearly documented evidence in an audit trail that findings emerged from the MMR study, transparent data analysis (interpretive transparency), and

congruency between data analysis and the complexity conceptual model (theoretical consistency) (Grembowski et al., 2014; O’Cathain, 2010).

Ethical considerations. The study protocol has received approval from the Hamilton Integrated Ethics Review Board (Project #3024-C, 3137). Informed, written consent or verbal consent for phone interviews will be obtained from all participants by the first author. Older adult participants will be advised that participation in the study will in no way affect their usual home care. As these interviews will be conducted in the home environment, if observations are made of safety issues, abuse, or neglect, the informed consent document explains that the researcher has a duty to alert the home care coordinator. Given many older adults receiving home care services may have some degree of cognitive impairment, a determination of ability to consent or participate will be made by the first author (an experienced gerontological nurse) before conducting the interview.

Significance and Implications

This proposed convergent MMR study to address the complexity of living with T2DM and UI in the context of MCC for older adults receiving home care services has several intended implications. Firstly, as the first study of this population in the home care context, practical clinical knowledge will be produced as the protocol is based on both clinical experience of a practice problem and evidence from a literature review (Dellinger & Leech, 2007). Grounding the protocol in current clinical, empirical, and conceptual knowledge will also ensure that the inferences made in the study will build on current understanding and meet the study’s goal (Dellinger & Leech, 2007). The

proposed study has disciplinary relevance as the future findings could be used to inform the development of a complex intervention to address the problem of UI for older adults with T2DM and MCC receiving home care services.

Secondly, the study will provide learnings on how MMR can be used to comprehensively understand a clinical dilemma and inform complex intervention design. The use of a theoretical framework to bind a MMR study is not typically done in health care research, but has great likelihood of generating results that would be helpful in planning interventions and health care delivery (Bazeley, 2018). The integration of the analysis of interRAI assessments in MMR to inform home care intervention design is not common but potentially beneficial to explore co-occurring patterns of MCC (such as T2DM and UI) and health outcomes (Mello et al., 2015).

Finally, the proposed study will lead to future inquiry related to UI and T2DM in older adults with MCC. Sequential studies will include co-design by health care professionals, older adults, and caregivers of the components of a complex intervention to manage UI in older adults with T2DM receiving home care services and a pragmatic, randomized, controlled trial of the newly described intervention.

Conclusion

The intent of this MMR project is to improve the understanding of the clinical complexity of older adults living with T2DM and UI in order to take practical steps forward to address the prevalent problem of UI in this population receiving home care. The structure of the study and the potential findings are well positioned to have utility to

inform and influence health care delivery and consequently prevent the negative health outcomes associated with T2DM, UI and MCC.

Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

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Appendix A

Older Adult Participant Interview Guide

1. I would like to learn about how you manage your diabetes and incontinence. I would also like to understand how the home care workers help you manage diabetes and incontinence. Could you describe for me what it is like to have diabetes and incontinence and have home care services?
2. Could you tell me about what an average day looks like for you as you manage diabetes and incontinence? Could you take me through a typical day? Could you tell me about what you did yesterday? What types of activities do you do to look after these conditions? Could you show me how you go about doing that activity?
3. What helps you manage your diabetes and incontinence? What makes it difficult to manage your diabetes and incontinence?
4. What does it feel like to have diabetes and incontinence? Can you tell me about a time when you were feeling sick?
5. Could you tell me about what your [relative/support person] does for you? What types of activities would you ask [applicable relative/support person] to do for you? Tell me about any activities you wish they would do.
6. Could you tell me about a time when the nurse [or PSW or your care coordinator] was talking to you about your diabetes (or incontinence)? Can you give me an example of something the nurse [or PSW or your care coordinator] does that is helpful to you in living with your diabetes and incontinence? Can you give me an example of what you wish they could do?

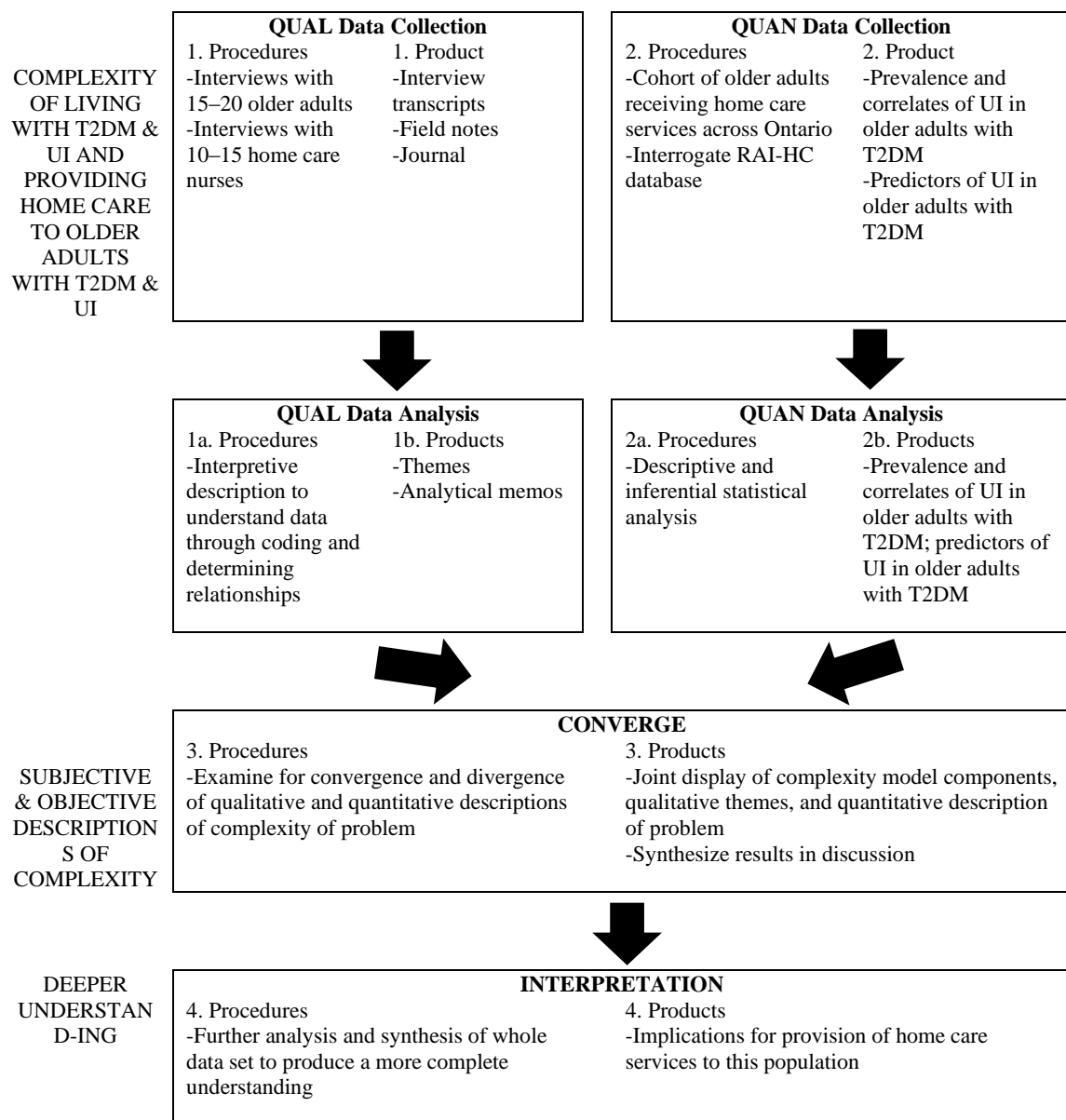
7. Can you tell me about any other community services that you use?
8. Could you tell me what the ideal home care services would look like for a person managing diabetes and incontinence?
9. Could you tell me about a time when you had to go to the emergency room or the hospital? What was happening? What were all the steps you took from when you first noticed you were feeling sick?
10. Is there anything else that we haven't talked about that you think would be important for me to know about your experiences living with diabetes and incontinence while receiving home care services?

Appendix B

Nurse Participant Interview Guide

1. Tell me about some experiences you have had caring for an older adult that has both diabetes and incontinence. Can you tell me about how you approach the care of an older adult that has both diabetes and incontinence? Would you describe for me how you decide what to do for a client with both diabetes and incontinence?
2. Can you describe for me what the functional abilities are like for your typical client with both diabetes and incontinence?
3. From your experience, what nursing interventions work best for an older adult with both diabetes and incontinence?
4. Thinking about the clients you see in your practice, do you think their income [and gender] affects how they manage their diabetes and incontinence?
5. If you were supervising a nursing student in the home environment, what would be the most important lessons you would want to tell them about working with older adults with diabetes and incontinence?
6. Tell me about what it is like working with older adults' caregivers, such as the spouse or child. How does this social support influence how your older adult clients manage their diabetes and incontinence?
7. Thinking about the clients you care for with diabetes and incontinence, tell me about what it is like working with other home care workers, such as their personal support workers or care coordinators. Can you give me an example? Could you tell me about how you approached your client's care in this situation?

8. If you were in charge of home care and could decide how to organize care, tell me about any changes you would make in how older adults with diabetes and incontinence are cared for in their homes.
9. Thinking about older adults with incontinence and diabetes, tell me about a time when you worked with your client's primary care physician [or nurse practitioner].
10. Could you tell me about a time when one of your clients with diabetes and incontinence had to go to the hospital? What happened? What did you do? Can you tell me all the different steps you took to see them from the home to the hospital?
11. Is there anything else that we haven't talked about that you think would be important for me to know about your experiences providing home care to older adults with diabetes and incontinence?



Note. Schematic adapted from p. 70 of Creswell & Plano Clark (2018).

Figure 1. *Diagram of the Proposed MMR Study*

Table 1

RAI-HC Health Outcome Scales

Scale	Description
Depression Rating Scale (DRS)	Clinical screen for depression.
Changes in Health, End-stage disease and Signs and Symptoms (CHESS)	Identifies frailty and health instability to recognize clients at risk of serious decline.
Activities of Daily Living (ADL) Self-Performance Hierarchy Scale	Measures client's self-performance in hygiene, toileting, locomotion, and eating.
Instrumental Activities of Daily Living (IADL) Difficulty Scale	Measures client's capacity in completing housework, meal preparation, and phone use.
Cognitive Performance Scale (CPS)	Describes client's cognitive status.

Note. Source: CIHI, 2013

Table 2

Definitions of Urinary Continence in Proposed Study and the RAI-HC

Dichotomous Classification	Continence Pattern	Description
Continent	Continent	Complete control, including cueing or prompting by a caregiver.
	Infrequently incontinent	Not incontinent over last 3 days, but client does have incontinent episodes (specifically, a recent history of incontinence).
	Occasionally incontinent	Less than daily episodes of incontinence (incontinent on 1 to 2 of the last 3 days).
Incontinent	Frequently incontinent	Incontinent daily but with some control present. For example, the client remains dry during the day but is incontinent at night.
	Incontinent	No bladder control and multiple daily episodes of incontinence all or almost all of the time.

Note. Source: Morris et al., 2012.

Table 3

Corresponding RAI-HC Items to Assess Characteristics and Health Service Utilization of Older Adults Receiving Home Care Services

Characteristics	Measured Variables
Sociodemographic	Age Sex Marital status Education level Primary language Limited funds
Psychosocial	Presence of primary caregiver living with client Primary caregiver status: (a) Unable to continue in caring activities; (b) Not satisfied with support received from friends, family; (c) Expresses feeling of distress, anger, or depression Loneliness Change in social activities last 90 days Depression Rating Scale
Community Resources	Living arrangement Home environment: (a) Inadequate heating/cooling; (b) Concern for personal safety
Functional	Activities of Daily Living Self-Performance Hierarchy Scale Instrumental Activities of Daily Living Difficulty Scale Cognitive Performance Scale
Clinical	Use of incontinence pads Bowel continence Morbid obesity Disease Diagnoses/Health Conditions (e.g., cerebrovascular accident, congestive heart failure, coronary artery disease, hypertension, dementia, urinary tract infection in last 30 days) Falls frequency Pressure ulcer Number of medications Changes in Health, End-stage disease and Signs and Symptoms Scale

Health Service Utilization	Formal care in last 7 days (e.g., personal support worker, nurse, physical therapy, day care) Time since last hospital stay Wound care dressing Emergency room use in past 90 days Physician visit in past 90 days
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Table 4

Joint Display of Quantitative and Qualitative Analysis

Complexity Model Components	QUAN	QUAL	
	Prevalence, Correlates and Risk Factors of UI from RAI-HC	Older Adults	Nurses
Health care system	e.g., proportion receiving nursing services, odds of recent ER use influencing continence status	Themes	Themes
Community resources	e.g., proportion living in home environment in disrepair, odds of living alone influencing continence status	Themes	Themes
Person	e.g., mean age, proportion male/female, difference in DRS related to continence status	Themes	Themes
Health	e.g., proportion with ADL impairment, difference in ADL impairment related to continence status	Themes	Themes
Social Support	e.g., proportion with primary caregiver unable to continue caregiving, odds of presence of caregiver influencing continence status	Themes	Themes
Population health and inequities	e.g., proportion with limited funds, odds of making financial trade-offs influencing continence status	Themes	Themes

Note. Model components are based on components of complexity conceptual model (Grembowski et al., 2014). QUAN = quantitative strand. QUAL = qualitative strand. ER = emergency room. DRS = Depression Rating Scale. ADL = activities of daily living.

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Supplementary File 1

Qualitative Research on the Experience of Living with Multiple Chronic Conditions

Authors, Year, Country	Design: Purpose	Sample	Results
Backman et al., 2018 Canada	Descriptive: To explore in detail the experience of older adults with MCC and caregivers during transitions across health care settings and identify areas of future interventions.	3 men and 6 women (4 older adults, 3 caregivers alone, 2 older adults/caregivers together) Ages 77.6 on average All older adults receiving home care services and some living with T2DM	Importance of being actively involved in care-planning at transitions (family as “critical advocates”, being organized for self-monitoring, acting on previous experiences). Positive transition experiences included care coordination and nurse involvement. Accessing community services important including home support and personalized care. Multiple challenges with follow-up care.
Eckerblad et al., 2015 Sweden	Descriptive: To explore the experiences of living with a “high symptom burden” from perspective of community dwelling older adults with MCC.	4 men and 16 women Age 84 on average Some receiving home care services and living with T2DM or “problems with urination” Recruited participants that scored high on symptom assessment scale from exercise RCT.	Overall theme: “to adjust and endure” (p. 323) Subthemes: feeling inadequate and limited in activities they used to do with ease; feeling dependent on partners, family and home care services; feeling dejected and tired by all of the co-occurring symptoms.
Gill et al., 2014 Canada	Descriptive: To explore the challenges experienced by patient-caregiver-physician triads to illuminate system	15 men and 12 women Age 82.3 on average Some receiving home care services and living with T2DM 27 informal caregivers (mostly wives) 4 family physicians	Frustrations expressed by patients: long wait times, poor communication between providers, poor care coordination for multiple medications, too little input from primary physician with medical trainees, no support for

Authors, Year, Country	Design: Purpose	Sample	Results
	improvements for managing MCC.	Tertiary academic health care centre in Toronto, Ontario	difficult decisions. Frustrations expressed by caregivers: long wait times, poor communication and lack of care coordinator, challenges with adhering to treatment and making decisions. Frustrations felt by physicians: lack of access to care when needed, poor communication with specialists, how to support client/caregiver with non-clinical issues, non-adherence to treatment.
Jarling et al., 2018 Sweden	Interpretive Description: To describe the meaning of home care from perspective of older adults with MCC living alone	4 men and 8 women Ages 77–90 Some living with T2DM	Experience of receiving home care described by overall theme “becoming a guest in your own home” (p. 4) and 4 subthemes: “adapting to a caring culture,” “feeling exposed,” “unable to influence care,” and “forced relations.”

Authors, Year, Country	Design: Purpose	Sample	Results
Newbould et al., 2012 England	Descriptive: To examine experiences of care planning discussions and care plans in England and explore barriers or facilitators to implementation of this approach.	12 men and 11 women Ages most >75 Some receiving home care services and living with T2DM 8 caregivers Urban and rural setting	Chronic illness management was mostly reactive, not proactive care planning. Participants were concerned about the future but did not discuss with health care providers. Some saw no need to plan ahead as perceived nothing could be done about conditions. Written care plans were exception.
Ploeg et al., 2017 Canada	Interpretive Description: To explore the experience of managing MCC in the community from the perspectives of older adults with MCC, family caregivers, and health care providers working in a variety of settings.	23 men and 18 women Ages >65 ≥3 chronic conditions with 1 being diabetes, dementia or stroke Some receiving home care services 47 caregivers 42 health care providers	Participants described the experience of managing MCC as: “overwhelming, draining and complicated,” organizing appointments and medications, “being split into pieces,” “doing what the doctor says,” reliance on caregivers, and difficulty accessing help.

Note. MCC = multiple chronic conditions; RCT = randomized control trial; T2DM = type 2 diabetes mellitus.

CHAPTER FOUR

TITLE: A cross-sectional study of the prevalence and correlates of urinary incontinence in older home-care clients with diabetes in Ontario, Canada

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JOURNAL: Submitted to *Canadian Journal of Diabetes* and formatted to the requirements of the journal. It is currently under review.

Abstract

Objectives: Urinary incontinence (UI) is a burdensome condition for older adults with diabetes receiving home-care services yet little is known about the prevalence and correlates of UI in this population. The objective of this cross-sectional study, informed by a complexity model, was to determine the prevalence and correlates of UI in older adults with diabetes receiving home care in Ontario, Canada.

Methods: Population-level data of the most recently completed Resident Assessment Instrument for Home Care from 2011-2016 for older (≥ 65 years) home-care clients with diabetes were analyzed. Older adults with daily or multiple daily episodes of UI were compared to those who were continent or experienced less than daily UI on sociodemographic, functional, psychosocial, and clinical variables. Multiple logistic regression was used to determine correlates of UI in this population.

Results: Of 118,519 older adults with diabetes, 39,945 (33.7%) experienced daily or multiple daily episodes of UI. Correlates of UI included: impaired function in activities of daily living (OR 5.31, 95% CI: 5.14, 5.50), cognitive impairment (OR 2.37, 95% CI: 2.28, 2.47), female sex (OR 1.87, 95% CI: 1.82, 1.93), multiple (≥ 2) chronic conditions (OR 1.83, 95% CI: 1.74, 1.93), presence of a distressed caregiver (OR 1.31, 95% CI: 1.27, 1.35), making economic trade-offs (OR 1.23, 95% CI: 1.11, 1.34), and falls (OR 1.22, 95% CI: 1.19, 1.26).

Conclusions: Urinary incontinence is common among older adults with diabetes using home-care services. Targeted interventions are required to address the social, functional, and clinical factors associated with UI in this population.

A cross-sectional study of the prevalence and correlates of urinary incontinence in older home-care clients with diabetes in Ontario, Canada

Introduction

Diabetes, including types 1 and 2, is a global public health concern as the worldwide prevalence is steadily increasing every year (1). Type 2 diabetes mellitus accounts for 90 to 95% of cases in Canada and worldwide (2,3). Diabetes affects 14 to 23% of older adults (aged ≥ 65 years) and 25% of older adults receiving home-care services (3,4). For older adults, diabetes is a serious metabolic disorder with life threatening and functionally detrimental complications (5). Older adults with diabetes are often living with multiple (≥ 2) chronic conditions and geriatric syndromes, such as urinary incontinence (4,5). Urinary incontinence (UI) is a common complication of diabetes that is associated with reduced quality of life, depression, and fractures (6,7). It is emotionally, physically, and functionally problematic not only for older adults but also their family caregivers (7). UI is a known risk factor for premature admission to long-term care (7,8). Consequently, the health-care needs of older home-care recipients with diabetes are increasingly complex due to the influence of multiple chronic conditions and geriatric syndromes and a preference to age-in-place (9,10).

Yet, research is limited regarding the prevalence and correlates of UI in older adults with diabetes receiving home-care services. A cross-sectional study of older men and women with diabetes enrolled in an American home-care program noted a 44% prevalence rate of UI (11). Another cross-sectional study in Ontario, Canada and Europe found that 48% of older adult home-care recipients with diabetes experienced UI (4). The

publicly reported rate of UI is 31.2% for all Ontario home care recipients receiving services from 2017 to 2018 (12).

Longitudinal cross-sectional research in younger women (mean age 63.5 years) with diabetes identified the following correlates of UI: higher body mass index, higher parity, lower physical activity, postmenopausal hormone use, and diuretic use (13). The effect of diabetes on UI in men is undetermined due to inability of research studies to differentiate development of urinary tract symptoms from benign prostatic hyperplasia or diabetes (14). UI is associated with multiple factors in older adults, including female gender, older age, age-related changes (i.e., decreased bladder capacity), medications that affect bladder function, functional impairment or dependence for toileting, cognitive impairment, sensory impairment, and chronic conditions (i.e., diabetes, stroke, depression or Parkinson's disease; 7,15,16).

To the authors' knowledge, only one cross-sectional study has examined the correlates of UI in older adults with diabetes receiving home care (11). In this study of 447 older adults, UI was associated with >85 years of age (OR 3.13, 95% CI: 2.15, 4.56), dependence on others for ambulation (OR 1.48, 95% CI: 1.19, 1.84), cognitive impairment (OR 1.41, 95% CI: 1.15, 1.73), and use of insulin (OR 2.62, 95% CI: 1.67, 4.13) or oral glucose-lowering medications (OR 1.81, 95% CI: 1.33, 2.45) (11). However, the generalizability of these findings is limited due to the small sample size, and the focus on older adults of predominantly Asian ethnicity receiving a unique home-care program to forestall long-term care placement (11).

Thus, a larger scale investigation is required to explore all the factors that potentially influence UI in older home-care recipients with diabetes, such as the presence of chronic conditions. This enhanced knowledge of the factors associated with UI would assist in identifying those most at risk and target the provision of home care to mitigate those risks. As such, the aim of this cross-sectional study was to determine the prevalence and correlates of UI in older adults with diabetes receiving home-care services in Ontario, Canada. The research questions for this study are as follows: Among older adults with diabetes receiving home-care services in Ontario, (a) what is the prevalence of UI?; (b) are there differences in the sociodemographic, functional, psychosocial, and clinical correlates between those with UI and without UI?; and (c) what are the sociodemographic, functional, psychosocial, and clinical predictors of UI?

Methods

Design and Setting

This cross-sectional study used population-level data from the Canadian Institute for Health Information (CIHI) on the most recently completed, standardized Resident Assessment Instrument for Home Care (RAI-HC) for Ontario long-stay clients (> 60 days; ≥ 65 years) with diabetes from 2011-2016 (the updated version of the RAI-HC, the interRAI Home Care, was implemented in Ontario in 2018). The RAI-HC is a validated, standardized and comprehensive assessment tool that gathers information on older adults' function, health, social support and service use (17-20).

Approximately 450,000 older adults receive home-care services annually in Ontario (21). Home-care services are funded through the Ministry of Health and Long-

term Care and planned and delivered by Local Health Integration Networks (LHINs). CIHI receives RAI-HC data from the LHINs, ensures data quality, and anonymizes the data for use in research and health-service planning. LHIN-employed care coordinators, most commonly registered nurses, are trained RAI-HC assessors and utilize the outputs of this tool to guide planning of community care and services (20). Groups of items in the RAI-HC trigger automatic flagging of Clinical Assessment Protocols indicating clients' needs in specific areas of function, such as, UI, falls, and pain (20). The outputs of the RAI-HC also include health outcome scales, such as the cognitive performance scale, which have been validated against gold-standard clinical assessment tools (17).

This study is the quantitative strand of a mixed methods study; the study protocol has been previously published (22). The larger study included qualitative strands that explored the experiences of both older adults with diabetes and UI receiving home-care services [23] and the home-care nurses caring for this population [24] as well as an integration of all strands into a mixed methods interpretation (22). A model of clinical complexity for persons with multiple chronic conditions was used to inform variable selection and regression modeling by considering a broad range of potential influencers of health outcomes (10). In this model, complexity is conceptualized as the gap between the needs of persons with multiple chronic conditions and the capacity of the health-care system and community resources to meet those needs (10). This needs-services gap is influenced by multiple components: the older adult's characteristics, values and preferences; health, function and well-being; and social support (10).

This study was conducted in accordance with the Tri-Council Policy Statement (25). Ethics approval for the study was received from the Hamilton Integrated Ethics Review Board (Project #3024-C).

Sample

The cohort included older adults living with diabetes receiving long-stay home-care services in Ontario from 2011-2016. The diabetes disease diagnosis in the RAI-HC includes both type 1 and type 2 diabetes; however, the majority (90–95%) of adults are living with type 2 diabetes (2,20). Older adults with an indwelling catheter or who had not voided in past three days were not included in the cohort as they likely would have different risk factors than those with UI.

Variables

UI is the dependent variable in this study and was dichotomized as either continence or incontinence. In the RAI-HC, continence status is determined based on episodes of incontinence over the past seven days (20). For the purposes of this study, the continence category included older adults who are continent as well as those who experienced less than daily episodes of UI. The incontinence category included older adults with daily or multiple daily episodes of UI. This dichotomy is clinically relevant as it is expected that the correlates of UI among older adults experiencing daily UI would be different from those older adults who experience less than daily UI (7).

Independent variables were selected from the RAI-HC items based on known risk factors for both diabetes complications and UI, components of the complexity model, and

availability in the RAI-HC (refer to Supplementary Table 1; 10). A range of sociodemographic (e.g., age, sex), functional (e.g., activities of daily living (ADL) self-performance hierarchy scale), psychosocial (e.g., depression rating scale), clinical (e.g., chronic conditions), and health service utilization (e.g., recent hospitalization) variables were included (4,6,7,16,26-30). Multiple chronic conditions was defined as two or more chronic conditions in addition to diabetes, given that 95% of older adults with diabetes have at least one other chronic condition (31).

Cut-offs for the scales were chosen for analysis based on previous research regarding the RAI-HC. The depression rating scale score range is 0–14 with a score of ≥ 3 indicating a potential or actual problem with depression (32). The ADL self-performance hierarchy scale ranges from 0–6 with higher scores indicating more impairment and a cut-off of ≥ 3 was selected to reflect moderate to severe ADL impairment (17,33). The instrumental activities of daily living (IADL) difficulty scale range is 0–6, with higher scores indicating greater difficulty (17). A cut-off of ≥ 4 was chosen to indicate great difficulty in one or more of the following areas: housework, meal preparation, and phone use (17,33). Cognitive Performance Scale scores range from 0–6 with higher scores indicating more severe cognitive impairment and a score ≥ 1 was chosen to capture any degree of cognitive impairment. The Changes in Health, End-stage disease and Signs and Symptoms Scale (CHESS) was designed to identify clients at risk of serious decline and is scored from 0–5 with higher scores indicating higher levels of medical instability and complexity (34,35). A cut-off of ≥ 3 was chosen to indicate greater risk of serious decline (36). The Method for Assessing Priority Levels (MAPLe) is an algorithm that categorizes

clients based on risks for adverse outcomes and a cut-off of ≥ 4 was chosen to indicate high to very high care needs (37). The institutional risk clinical assessment protocol identifies older adults who are at risk of moving to long-term care within months based on impaired physical and cognitive functioning and declining health (8). The urinary clinical assessment protocol identifies older adults with UI in whom bladder function could be improved or prevented from worsening (8).

Statistical Methods

This article adhered to the reporting guidelines for studies conducted using observational routinely conducted data (see Supplementary Table 2; 38). Analyses were performed using SPSS version 24 for Windows; except for polychoric correlations (association between categorical variables) where SAS software version 9.4 was used. Data were missing for some of the scales and variables that are not routinely collected at every assessment (education level, time since last hospital stay, service use); however, these variables were not included in model building (see Table 1).

The first step of the analysis was to generate descriptive statistics to describe the frequencies (percentages) of categorical data and means (standard deviations) of the continuous data to answer research questions (a) and (b). Independent *t* tests for continuous variables and chi-square tests of independence for categorical variables were used to examine research question (b) to identify characteristics of older adults that distinguish those with and without UI. The bivariate association between each independent variable and the dependent variable were tested using logistic regression. For population-level studies using RAI-HC data, virtually all group comparisons are

statistically significant due to large sample sizes even though group differences may not be clinically significant (39,40). Variables with odds ratios (OR) of ≥ 1.2 have been used to determine clinical significance in previous RAI-HC research, thus this criterion was used to determine significance for inclusion in a multivariable model (39,40).

The second step of analysis was to evaluate multicollinearity by examining polychoric correlations among the candidate independent variables (41). Variable pairs with a correlation of ≥ 0.5 (or -0.5) were considered highly correlated (42). If two variables were found to be highly correlated, the variable with the lower OR from the bivariate analysis was eliminated.

The third step of the analysis was multivariable logistic regression to answer research question (c). Rather than including individual diseases, a multiple chronic conditions binary variable was created (≥ 2 conditions compared to ≤ 1 condition) from a count of the disease diagnoses. The complex scales (i.e., CHESS, MAPLe) and the institutional clinical assessment protocol were only used for descriptive purposes as they are comprised of many variables and would be highly correlated with RAI scales considered for inclusion as independent variables in the multivariable model (e.g., cognitive performance scale). Finally, other variables that would not be useful to identify older adults at risk of UI in clinical practice were described but not included in the multivariable regression (i.e., home-care and health-care utilization variables). A preliminary main-effects model was produced. A goodness of fit measure (*c* statistic), and sensitivity and specificity measures were used to judge the resulting model. The Hosmer and Lemeshow test, which is customarily used to assess the fit of a model in

logistic regression, was not used because with such a large sample, even small differences between observed and expected values are judged to be statistically large and the null hypothesis that the model fits has to be rejected (41,43).

Results

The cohort included 118,519 older adults (≥ 65 years) living with diabetes and receiving home-care services in Ontario from 2011-2016. The sample was an average of 80.7 years ($SD=7.81$) and most were women (57.6 %). The sample had a mean of 5.6 ($SD=2.17$) chronic conditions in addition to diabetes, and taking on average 8.2 ($SD=1.64$) medications daily (see Table 1). About one-third (33.7%) of this sample of older adults with diabetes reported daily or multiple daily episodes of UI.

Older adults with UI differed significantly from those without UI on the following characteristics (see Table 1 and Supplementary Table 3). Older adults with UI were on average 2.2 years older than those without UI (82.2 and 80.0 years respectively) and had more chronic conditions in addition to diabetes (difference 1.69; 95% CI 1.66, 1.71). A greater proportion of older adults with UI compared to those without UI were female (63.6% compared to 54.5%). Almost all of those with UI (90%) had some degree of cognitive impairment compared to 71.0% of those without UI. A greater proportion of those with UI than those without UI were impaired in ADLs (53.6% compared to 14.5%) and IADLs (95.9% compared to 83.8%), had fallen in the past 90 days (50.1% compared to 42.3%), and had a recent urinary tract infection (10.7% compared to 4.8%). As well 61.1% of older adults with UI also had fecal incontinence compared to 16.4% of those without UI. A greater proportion of older adults with UI (84.9%) triggered the UI clinical

assessment protocol to improve UI or prevent decline than older adults without UI (41.1%).

The caregivers of older adults with UI more frequently felt unable to continue in their caregiving duties (27.5%) and experienced feelings of distress, anger or depression (40.6%) compared to caregivers of persons without UI (16.4% and 26.2%, respectively). More of the older adults with UI (76.2%) compared to those who were continent (55.2%) were receiving care from a personal support worker. A minority of older adults in both the incontinence (28.5%) and continence groups (29.9%) were receiving nursing support.

The following variables had ORs that met or exceeded the cut-off of 1.2 for establishing clinical significance, and as such, were included in the multivariable model: sex, economic trade-offs (e.g., among purchasing medications, food, etc due to limited funds), cognitive performance scale, depression rating scale, ADL self-performance hierarchy scale, caregiver distress, falls, and multiple chronic conditions. The IADL Difficulty Scale and the ADL Self-Performance Hierarchy Scale were highly correlated (>0.5) so the IADL scale was not included in the model.

In the final multivariable model, ADL impairment, cognitive impairment, female sex, the presence of ≥ 2 chronic conditions, caregiver distress, falls, and economic trade-offs were significantly associated ($OR \geq 1.2$) with UI in older adults with diabetes (refer to Table 2). This model correctly classified incontinence and continence well at a rate of 75.7% and has acceptable discrimination ability with a c statistic of 0.74 (33). Older adults with incontinence were 5.31 times more likely to be impaired in carrying out

ADLs (95% CI: 5.14, 5.50) and 2.37 times more likely to have some degree of cognitive impairment compared to those without UI (95% CI: 2.28, 2.47). Women were 1.87 times more likely than men to have UI (95% CI: 1.82, 1.93). Those experiencing UI were 1.83 times more likely to be living with two or more chronic conditions (in addition to diabetes) compared to those without UI (95% CI: 1.74, 1.93). For older adults with UI, their caregivers were 1.31 times more likely to experience feelings of distress, anger, or depression, compared to caregivers of older adults without UI (95% CI: 1.27, 1.35). Those with UI were 1.23 times more likely to make economic trade-offs compared to those without UI (95% CI: 1.11, 1.34) and 1.22 times as likely to have fallen in the past 90 days (95% CI: 1.19, 1.26).

Discussion

The findings suggest that about one-third (33.7%) of older adults with diabetes receiving home-care services in Ontario, Canada have UI. The study also identified the following correlates of UI in older adults with diabetes receiving home-care services: ADL impairment, cognitive impairment, female sex, multiple chronic conditions, caregiver distress, economic trade-offs, and falls. This study of the prevalence and correlates of UI in this population of older adults with diabetes receiving home care has generated several key findings.

First, UI is common in older adults with diabetes (33.7%). The finding that UI is a highly prevalent problem for home-care recipients is supported by the publicly reported UI rate (31.2%) for all Ontario home-care recipients receiving services from 2017 to 2018 (12). The prevalence rate of UI in older adults with diabetes receiving home care in

the current study was lower than rates of 44% and 48% noted in the two cross-sectional studies (4,11). One explanation for this difference is that the definition of UI varied among the studies. While the current study defined UI as a daily episode, other studies defined UI as any amount of urine loss (i.e., occasional incontinence; 4,11). Specifically, in the study by Vetrano et al. also using RAI-HC data, they defined incontinence as including those with any frequency of urine loss and wearing catheters (excluded in this study), likely explaining their higher prevalence rate of 48% (11).

Second, UI in older adults with diabetes receiving home-care services has multiple contributing factors. This study uniquely identified that UI is associated with economic trade-offs, caregiver distress, and multiple chronic conditions, highlighting the complexity of factors contributing to UI in this population. The finding that female sex, falls, and cognitive and ADL impairments are contributing factors to UI in older adults is supported by current understanding and best practice guidelines (7,16,44). The result that older home-care recipients with UI were also living with the geriatric syndromes of falls and cognitive impairment is consistent with evidence that geriatric syndromes, such as UI, result from the accumulated effect of impairments in multiple domains (16). Thus, the management of UI for this population must include interventions directed at each of these contributing factors in order to promote continence.

Third, older adults with diabetes and UI were 7.42 times more at risk for admission to long-term care, compared to those who were continent (95% CI 7.16, 7.68). This finding is consistent with previous literature noting incontinence as a known driver of long-term care placement and supports the importance of improving the detection and

management of UI in the home-care setting to enable aging-in-place (7,8). However, the entire study population of older adults were receiving remarkably little health-professional care that could potentially mitigate risk for institutionalization. The minority (28.5%) of older adults with diabetes experiencing UI were receiving nursing care, similar to those who were continent (29.9%). Even fewer older adults with UI had received home care from occupational therapists or physiotherapists (16.9% and 13.4%, respectively).

Implications

Given the high prevalence of UI in older home-care recipients with diabetes, proactive screening to detect UI should occur in all health-care professional contacts with these older adults. Older adults with diabetes receiving home-care services should be added to diabetes best-practice guidelines as a population requiring a special focus, as is done for the long-term care population, given the evidence of clinical complexity in home-care recipients revealed by this study (5). Specifically, care-planning with older adults regarding glycemic control targets should consider the negative impact of hyperglycemia and polyuria (large amount of urine production) on UI in addition to function and frailty (1).

As well, these findings highlight a need to assess for functional and cognitive impairments, multiple chronic conditions, caregiver distress, financial limitations, and falls when approaching the problem of UI in older adults receiving home-care services and to provide the necessary supportive and restorative care. For example, home-care providers should consider the response to the RAI-HC item regarding making economic

trade-offs and intervene to ensure that older adults have filed their tax returns and receive their allowed benefits (45). Supportive and restorative interventions, such as exercise, balance training, mobilization, and cognitive-promoting activities, should be part of the care plan to address functional and cognitive impairments and falls (46). Also, caregivers must be included in care-planning discussions as interventions may be needed to bolster their ability to continue caregiving and support continence-promoting strategies, such as prompted voiding.

While UI is a provincial home-care quality indicator, there is not a parallel quality improvement plan to address UI in older adults (47). The common prevalence of UI in this population, highlights the need for a provincial strategy that emphasizes the prevention, early detection, and management of UI in Ontario home-care recipients. High quality evidence has demonstrated that self-management support by nurses and other health-care professionals can improve outcomes for both UI and diabetes (28,48). This strategy would need to enhance the relatively low provision of interprofessional team support, triage interprofessional team services to clients most at risk of poor outcomes, and leverage the existing support of personal support workers. Thus, specific criteria (based on the correlates of UI reported in this study) and guidelines for an interprofessional approach to improve the detection and management of UI in older adults with diabetes and multiple chronic conditions is required.

Strengths and Limitations

Key strengths of this study were the use of RAI-HC data that reliably captures comprehensive information about older adults and the very large sample of older home-care recipients. As well, the use of the RAI-HC allows for international comparison with other home-care programs that use this standardized assessment. The study did have some limitations. There are known contributing factors of UI that are not collected in the RAI-HC, such as body mass index or parity. As well, how long older adults had been living with diabetes, measures of glycemic control (i.e., A1C), or their current medications were not available in this data. Thus, these missing variables could generate potential residual confounding. Finally, due to the cross-sectional design, the identified factors are not causes of incontinence but rather factors correlated with UI.

Conclusions

The findings from this study will help to raise awareness of the magnitude of the problem and the important role of home care in preventing and managing UI in this population. Diabetes care and continence promotion in older home-care recipients must include interventions that target multiple correlates of UI. Future research is required to understand current health-care service delivery for this population in order to plan, test, and evaluate a complex, interprofessional home-care intervention to manage UI in older adults with diabetes. As well, future research efforts should examine if there are differences in the correlates of UI by gender, outcomes associated with UI, and the relationship of frailty, glycemic control, and UI in older adults with diabetes using home-care services. The correlates of UI should also be examined for those with any degree of

UI compared to those are not experiencing UI to further extend the presentation of UI in this population.

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Author Contributions

MN, MMR, DS, and JP contributed to the conception and design of the study. All authors participated in the analysis. MN drafted the manuscript and all authors revised it critically for important intellectual content and gave final approval of the version to be published. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Table 1

Total Population Characteristics and Characteristics Associated with Urinary Incontinence in Older Adults with Diabetes Receiving Home Care

Variable	Population	Group by Continence Status		Odds of UI
	n (%)	n (%)		
	Older adults with diabetes (N=118,519)	Continence (n=78,574)	Incontinence (n=39,945)	OR (95% CI)
Characteristics				
Sex				
Female	68,214 (57.6)	42,791 (54.5)	25,423 (63.6)	4.70 (4.54, 4.87)
Male (reference)	50,300 (42.4)	35,778 (45.5)	14,522 (36.4)	
Marital status				
Never married, widowed, divorced	69,797 (58.9)	45,107 (57.4)	24,690 (61.8)	1.20 (1.17, 1.23)
Married (reference)	48,720 (41.1)	33,465 (42.6)	15,255 (38.2)	
Education ^a				
No schooling	21,721 (31.1)	14,405 (30.2)	7,316 (33.0)	1.14 (1.10, 1.18)
Some schooling (reference)	48,115 (68.9)	33,287 (69.8)	14,828 (67.0)	
Trade-offs due to limited funds	1,927 (1.6)	1,252 (1.6)	675 (1.7)	1.23 (1.12, 1.35)
Social activity decline ^b	47,502 (45.9)	33,052 (46.0)	14,450 (45.8)	0.99 (0.96, 1.02)
Older adult feels lonely ^c	16,324 (15.8)	11,314 (15.8)	5,010 (15.9)	1.01 (0.98, 1.05)
CPS ≥ 1 ^d	91,709 (77.4)	55,084 (71.0)	35,905 (90.0)	3.63 (3.50, 3.76)
DRS ≥ 3	28,101 (23.7)	17,301 (22.0)	10,800 (27.0)	1.31 (1.28, 1.31)
Moderate/severe ADL impairment	56,678 (47.8)	11,406 (14.5)	21,414 (53.6)	6.81 (6.62, 7.00)
IADL great difficulty in ≥ 1 areas	113,269 (95.6)	65,833 (83.8)	38,326 (95.9)	4.58 (4.34, 4.83)
Falls ≥ 1 last 90 days	53,229 (44.9)	33,230 (42.3)	19,999 (50.1)	1.37 (1.34, 1.40)
Multiple chronic conditions ≥ 2	105,030 (88.6)	65,530 (85.9)	37,500 (93.9)	2.51 (2.40, 2.63)
CHESS ≥ 3 ^e	32,690 (27.6)	19,065 (24.3)	13,625 (34.2)	1.62 (1.57, 1.66)
MAPLe ≥ 4 ^f	64,166 (54.1)	36,761 (46.8)	27,405 (68.7)	2.49 (2.42, 2.55)

Variable	Population	Group by Continence Status		Odds of UI
	n (%)	n (%)		
	Older adults with diabetes (N=118,519)	Continence (n=78,574)	Incontinence (n=39,945)	OR (95% CI)
Family Caregiver				
Caregiver unable to continue	23,848 (20.1)	12,875 (16.4)	10,973 (27.5)	1.93 (1.88, 1.99)
Caregiver experiences feelings of distress, anger, or depression	36,751 (31.0)	20,550 (26.2)	16,201 (40.6)	1.94 (1.88, 1.98)
Elimination				
Urinary tract infection last 30 days	8,081 (6.8)	3,800 (4.8)	4,281 (10.7)	2.36 (2.26, 2.47)
Fecal incontinence	37,272 (31.4)	12,856 (16.4)	24,416 (61.1)	8.04 (7.82, 8.26)
Health care utilization				
Hospitalization past 180 days ^g	35,207 (29.7)	26,062 (33.1)	9,145 (22.9)	1.37 (1.31, 1.43)
Physician visit last 7 days ^h	38,860 (32.8)	25,903 (33.0)	12,957 (32.5)	0.98 (0.95, 1.00)
ER visit last 90 days	27,906 (23.5)	18,747 (23.9)	9,159 (22.9)	0.95 (0.92, 0.98)
Institutional CAP triggered ⁱ	78,567 (66.3)	42,693 (54.3)	35,874 (89.8)	7.42 (7.16, 7.68)
Urinary incontinence CAP triggered ^j	66,091 (55.8)	32,211 (41.1)	33,880 (84.9)	8.04 (7.82, 8.32)
Home care utilization past week				
Personal support worker ^k	65,659 (55.4)	40,326 (55.2)	25,333 (76.2)	2.61 (2.53, 2.69)
Visiting nurse ^l	31,371 (29.5)	21,904 (29.9)	9,467 (28.5)	0.93 (0.91, 0.93)
Physiotherapy ^m	14,400 (13.5)	9,948 (13.6)	4,452 (13.4)	0.98 (0.95, 1.02)
Occupational therapy ⁿ	18,433 (17.3)	12,824 (17.5)	5,609 (16.9)	0.96 (0.92, 0.99)
Day program ^o	3,515 (3.3)	2,212 (3.0)	1,303 (3.9)	1.42 (1.32, 1.52)
Variable	Population	Group by Continence Status		Mean Difference
	Older adults with diabetes (N=118,519)	Continence (n=78,574)	Incontinence (n=39,945)	
	Mean (SD)	Mean (SD)	Mean (SD)	Mean difference (95% CI)
Age (years)	80.72 (7.81)	79.98 (7.79)	82.17 (7.63)	2.20 (2.10, 2.29)
Number of chronic conditions	5.56 (2.17)	5.00 (2.06)	6.68 (1.93)	1.69 (1.66, 1.71)

Variable	Population	Group by Continence Status		Odds of UI
	n (%)	n (%)		
	Older adults with diabetes (N=118,519)	Continence (n=78,574)	Incontinence (n=39,945)	OR (95% CI)
Number of medications	8.18 (1.64)	8.12 (1.68)	8.31 (1.53)	0.19 (0.17, 0.21)

Note. OR = odds ratio. CI = confidence interval. CPS = Cognitive Performance Scale. DRS = depression rating scale. Institutional CAP = Institutional Risk Clinical Assessment Protocol flags risk of entering a long-term care home in the coming months. ADL = activities of daily living. IADL = instrumental activities of daily living. CHESS = Changes in Health End-Stage Disease and Signs and Symptoms. MAPLe = Method for Assessing Priority Levels. ER = emergency room.

Items missing, unknown or not applicable for initial assessment in continence and incontinence groups as follows: ^an=30,882 and 17,801; ^bn=6,763 and 8,383; ^cn=6,764 and 8,363; ^dn=5 and 5; ^en=128 and 53; ^fn=67, 27; ^gn=35,145 and 27,368; ^hn=158 and 77; ⁱn=7 and 7; ^jm=179; ^kn=5,413 and 6,707; ^ln=5,410 and 6,703; ^mn=158 and 77; ⁿn=5,408 and 6,705; and ^on=5,409 and 6,703.

Table 2

Factors Significantly Associated with Urinary Incontinence in Older Home Care Clients with Diabetes: Multivariable Logistic Regression Results

Factors	Odds Ratio (95% Confidence Interval)
Sex (reference: male)	1.87 (1.82, 1.93)
Economic trade-offs due to limited funds (reference: no trade-offs)	1.23 (1.12, 1.34)
Cognitive Performance Scale ≥ 1 (reference: no impairment)	2.37 (2.28, 2.47)
Moderate/severe activities of daily living impairment (reference: no/mild impairment)	5.31 (5.14, 5.50)
Caregiver experiences feelings of distress, anger, or depression (reference: no)	1.31 (1.27, 1.35)
Multiple chronic conditions ≥ 2 in addition to diabetes (reference: ≤ 1 chronic condition)	1.83 (1.74, 1.93)
Falls ≥ 1 last 90 days (reference: no falls)	1.22 (1.19, 1.26)
Depression Rating Scale ≥ 3 (reference: no signs/symptoms)	1.01 (0.97, 1.04)

Note: This model correctly classifies incontinence and continence well at a rate of 75.7%, and has acceptable discrimination ability with a *c* statistic of 0.74.

Supplementary Table 1

RAI-HC Variables Included in the Study

Variables	Definition/Measurement
Sociodemographic	
Age	Years
Sex	Female Male (reference)
Marital status	Never married, widowed or divorced Married (reference)
Education level	Grade 8 or less Highschool, technical school, college or university (reference)
Economic trade-offs among purchasing prescribed medications, sufficient home heat, necessary physician care, adequate food, or home care because of limited funds over past month	Yes No (reference)
Functional	
Activities of Daily Living Self-Performance Hierarchy Scale	Moderate/severe impairment (≥ 3) No/mild impairment (0–2; reference)
Instrumental Activities of Daily Living Difficulty Scale	Great difficulty in ≥ 1 area (≥ 4) No difficulty/some difficulty in ≥ 1 area (housework, meal preparation, phone use; 0–3; reference)
Cognitive Performance Scale	Any degree of impaired cognition (≥ 1) Intact cognition (0; reference)
Psychosocial	
Presence of primary caregiver living with client	Yes No/no such helper (reference)
Primary caregiver status: unable to continue in caring activities	Yes No (reference)
Primary caregiver status: expresses feelings of distress, anger, or depression	Yes No (reference)
Feels lonely	Yes No (reference)
Decline in social activities compared to 90 days ago	Decline No decline (reference)
Depression Rating Scale	Potential or actual problem with depression (≥ 3)

Variables	Definition/Measurement
	No indication of depression (0–2; reference)
Clinical	
Urinary incontinence	Daily or multiple daily episodes of incontinence (dependent variable) Continent/less than daily episodes of incontinence
Bowel incontinence	Any degree of incontinence Continent (reference)
Obesity	Yes No (reference)
Number of conditions in addition to diabetes	Multiple chronic conditions (≥ 2) ≤ 1 chronic condition (reference)
Chronic conditions (diabetes, hypertension, congestive heart failure, coronary artery disease, chronic obstructive pulmonary disease, irregular pulse, peripheral vascular disease, arthritis, osteoporosis, hip fracture, any psychiatric diagnosis, cerebral vascular accident, Alzheimer's disease, dementia (other than Alzheimer's), Parkinsonism, multiple sclerosis, hemiparesis, head trauma, glaucoma)	Present Not present (reference)
Urinary tract infection in last 30 days	Yes No (reference)
Falls in last 90 days	≥ 1 fall No falls (reference)
Pressure ulcer	Yes No (reference)
Number of medications	Number
Changes in Health, End-stage disease and Signs and Symptoms Scale (CHESS)	Greater risk of serious decline (≥ 3) Less risk of serious decline (≤ 2 ; reference)
Method for Assessing Priority Levels (MAPLe)	High to very high care needs (≥ 4) Low/mild/moderate care needs (≤ 3 ; reference)
Health Service Utilization	
Formal care (personal support worker, visiting nurse, physical therapy, occupational therapy, day care, wound dressing)	Yes No (reference)

Variables	Definition/Measurement
Hospitalization in last 180 days	Yes No (reference)
Emergency room visit in last 90 days	Yes No (reference)
Physician visit in last 7 days	Yes No (reference)
Institutional Clinical Assessment Protocol	Yes, triggered No, not triggered (reference)
Urinary Incontinence Clinical Assessment Protocol	Yes, triggered No, not triggered (reference)

Supplementary Table 2

Reporting of Studies Conducted using Observational Routinely-collected Data
(RECORD) Checklist of Recommendations for the Reporting of Studies Conducted Using Routinely Collected Health Data

Section of study	#	RECORD Items	Reported
Title and abstract	1	1.1 Type of data used should be specified in the title or abstract. When possible, the name of the databases used should be included.	Abstract
		1.2 If applicable, the geographic region and time frame within which the study took place should be reported in the title or abstract.	Title and abstract
		1.3 If linkage between databases was conducted for the study, this should be clearly stated in the title or abstract	N/A
Introduction			
Background rationale	2	Explain the scientific background and rationale for the investigation being reported.	Introduction
Objectives	3	State specific objectives, including any pre-specified hypotheses	Introduction
Methods			
Study Design	4	Present key elements of study design early in paper.	Methods
Setting	5	Describe the setting, location, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	Methods
Participants	6	6.1 The methods of study population selection (such as codes or algorithms used to identify subjects) should be listed in detail.	Methods (Sample)
		6.2 Any validation studies of the codes or algorithms used to select the population should be referenced. If validation was conducted for this study and not published elsewhere,	N/A (population sample)

		detailed methods and results should be provided.	
		6.3 If the study involved linkage of databases, consider use of a flow diagram or other graphical display to demonstrate the data linkage process, including the number of individuals who were linked at each stage.	N/A
Variables	7	A complete list of codes and algorithms used to classify exposures, outcomes, confounders, and effect modifiers should be provided. If these cannot be reported, an explanation should be provided.	Methods (Variables) Supplementary Table 1
Data sources /measurement	8	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group.	Methods (Variables) Table 1
Bias	9	Describe any efforts to address potential sources of bias	Methods
Study size	10	Explain how the study size was arrived at.	Methods
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why.	Methods (Variables) Supplementary Table 1
Statistical methods	12	12.1 Describe all statistical methods, including those used for confounding. 12.2 Describe any methods used to examine subgroups and interactions. 12.3 Explain how missing data were addressed. 12.4 If applicable, describe analytical methods taking account of sampling strategy. 12.5 Describe any sensitivity analyses.	Methods N/A Methods (Statistical Methods) N/A
Data access and cleaning		12.6 Authors should describe the extent to which the investigators had access to the database population used to create the study population.	Methods (Statistical Methods) Methods (Design and Setting)

		12.7 Authors should provide information on the data cleaning methods used in the study.	Methods (Design and Setting)
		12.8 State whether the study included person-level, institutional-level, or other data linkage and methods of linkage quality evaluation should be provided.	N/A
Results			
Participants	13	Describe in detail the selection of the persons included in the study, including filtering based on data quality, data availability, and linkage. The selection of included persons can be described in the text and/or by means of the study flow diagram.	Methods (Sample)
Descriptive Data	14	14.1 Give characteristics of study participants and information on exposures and potential confounders.	Results Tables 1 and 2 Supplementary Table 3
		14.2 Indicate number of participants with missing data for each variable of interest	Table 1
		14.3 Summarize follow-up time.	N/A
Outcome Data	15	Report numbers of outcome events or summary measures.	Results Tables 1 and 2
Main Results	16	16.1 Give unadjusted estimates, and if applicable, confounder-adjusted estimates and their precision. Make clear which confounders were adjusted for and why they were included.	Results Tables 1 and 2
		16.2 Report category boundaries when continuous variables were categorized.	Methods (Variables)
		16.3 If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period.	N/A
Other Analyses	17	Report other analyses done (e.g., analyses of subgroups and interactions and sensitivity analyses).	Results Table 2 Supplementary Table 3

Discussion			
Key Results	18	Summarize key results with reference to study objectives.	Discussion
Limitations	19	Discuss the implications of using data that was not created or collected to answer the specific research question(s). Include discussion of misclassification bias, unmeasured confounding, missing data, and changing eligibility over time, as they pertain to study being reported.	Discussion (Strengths and Limitations)
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	Discussion
Generalizability	21	Discuss the generalizability (external validity) of the study results.	Discussion (Strengths and Limitations)
Other Information			
Funding	22	22.1 Give the source of funding and the role of funders for the present study, and, if applicable, for the original study on which the present article is based	Funding
Accessibility of protocol, raw data, and programming code		22.2 Authors should provide information on how to access any supplemental information such as the study protocol, raw data, or programming code.	Confidentiality agreement between the authors and CIHI prohibit the sharing of the raw data requests can be made to CIHI to access databases at the record level (www.cihi.ca). Analyses done within SPSS using standard drop-down menus.

Note. Taken from Benchimol et al. (30) reporting statement. # = item number. N/A = not applicable in this study. CIHI = Canadian Institute for Health Information.

Supplementary Table 3

Additional Characteristics Associated with Urinary Incontinence in Older Adults with Diabetes Receiving Home Care

Variable	Group by Continence Status		Odds of UI
	n (%)		
	Continence (n=78,574)	Incontinence (n=39,945)	OR (95% CI)
Cardiorespiratory conditions			
Hypertension	56,670 (75.9)	31,660 (79.3)	1.27 (1.24, 1.31)
Congestive heart failure	14,863 (18.9)	8,047 (20.1)	1.08 (1.05, 1.11)
Coronary artery disease	26,761 (34.1)	13,803 (34.6)	
Chronic obstructive pulmonary disease	15,894 (20.2)	7,856 (19.7)	
Irregular pulse	12,048 (15.3)	6,847 (17.1)	1.14 (1.11, 1.18)
Peripheral vascular disease	8,325 (10.6)	4,804 (10.2)	
Musculoskeletal conditions			
Arthritis	39,687 (50.5)	22,697 (56.8)	1.29 (1.26, 1.32)
Osteoporosis	13,173 (16.8)	8,350 (20.9)	1.31 (1.27, 1.35)
Hip fracture	2,837 (3.6)	1,941 (4.9)	1.36 (1.29, 1.45)
Neurological/mental health conditions			
Dementia	13,393 (17.0)	13,109 (32.8)	2.21 (2.15, 2.27)
Psychiatric diagnosis	12,375 (15.7)	8,452 (21.2)	1.43 (1.39, 1.48)
Stroke	14,378 (18.3)	11,126 (27.9)	1.72 (1.68, 1.77)
Alzheimer’s Disease	3,857 (4.9)	3,794 (9.5)	2.03 (1.94, 2.13)
Parkinson’s	2,642 (3.4)	2,465 (6.2)	1.89 (1.77, 2.00)
Multiple sclerosis	263 (0.3)	195 (0.5)	1.46 (1.21, 1.76)

Variable	Group by Continence Status		Odds of UI
	n (%)		
	Continence (n=78,574)	Incontinence (n=39,945)	OR (95% CI)
Hemiparesis	1,532 (1.9)	1,636 (4.1)	2.14 (2.00, 2.31)
Head trauma	898 (1.1)	652 (1.6)	1.43 (1.30, 1.59)
Other			
Glaucoma	6,521 (8.3)	3,721 (9.3)	1.18 (1.13, 1.23)
Obesity	5,205 (6.6)	3,406 (8.5)	1.31 (1.26, 1.37)
Pressure ulcer	4,111 (5.2)	4,928 (12.3)	2.55 (2.44, 2.66)
Primary caregiver lives with older adult	42,400 (54.0)	21,430 (53.6)	

Note. OR = odds ratio. OR only presented for statistically significant differences.

CHAPTER FIVE

TITLE: The complexity of living with diabetes and urinary incontinence for older adults receiving home-care services: An interpretive description study

AUTHORS: Northwood, M., Ploeg, J., Markle-Reid, M., & Sherifali, D.

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Abstract

About one third of older adults with diabetes receiving home-care services experience urinary incontinence. However, experiential knowledge is lacking on how these older adults live with diabetes and incontinence. Interpretive description methodology was used to explore the experiences of 18 older adults with diabetes and urinary incontinence receiving home-care services in Ontario, Canada. Five themes emerged from the findings: (a) enduring urinary incontinence: “patch it in pads”; (b) struggling to manage diabetes, incontinence, and multiple chronic conditions: “a balancing act”; (c) covering the costs of care: “I can’t afford it”; (d) counting on a caregiver: “he does everything”; and (e) home-care services not meeting my needs: “it’s not individual.” These findings suggest that living with urinary incontinence and diabetes is a complex and challenging experience. This evidence could inform the provision of comprehensive home care to support self-care for this population.

The complexity of living with diabetes and urinary incontinence for older adults
receiving home care services: An interpretive description study

Introduction

Urinary incontinence (UI) is a common and burdensome condition among older adults with type 2 diabetes mellitus (T2DM) receiving home-care services. A cross-sectional study of older adults with T2DM receiving home-care services in Ontario, Canada, found that 33.7% experienced UI (Northwood et al., 2019a). With approximately 1.3 million older adults receiving home-care services annually in Canada, UI represents a very common problem (Better Home Care in Canada Partners [BHCCP], 2016). Older adults with UI are at greater risk for depression, falls, fractures, functional decline, and premature institutionalization than those without UI (Coll-Planas, Denking, & Nikolaus, 2008; Dugan et al., 2000; Wagg et al., 2016). This is particularly relevant as most older adults want to remain in their own homes, avoid long-term care placement, and will require UI care to do so (BHCCP, 2016). The current health-care system is similarly focused on aging-in-place to account for older adults' preferences but also to address fiscal pressures related to an aging population (Canadian Institute for Health Information [CIHI], 2018).

T2DM can be understood as multiple chronic conditions (MCC) given the association between T2DM and other chronic conditions, such as kidney disease, cognitive impairment, and depression (Sherifali & Meneilly, 2016; Sinclair et al., 2012; Vetrano et al., 2016). MCC is defined as two or more conditions that require ongoing care and attention and is associated with poor quality of life and functional disability

(BHCCP, 2016; CIHI, 2018). A cross-sectional study of older adults with T2DM found that 90% had at least one comorbid condition and 40% had five or more (Gruneir et al., 2016). Unfortunately, UI is often untreated or undertreated in older adults with T2DM, placing them at risk for negative consequences (American Geriatrics Society, 2013; Brown et al., 2005).

To our knowledge, no qualitative research has been conducted on older home-care clients' experiences living with UI and T2DM. Some qualitative descriptive research has explored the experiences of living with diabetes for older adults. These participants experienced challenges in self-managing, such as forgetting to take medications or feeling too unwell to exercise (Carolan-Olah & Cassar, 2018; Joo & Lee, 2016; Song et al., 2009). Older adults described benefiting from assistance with self-management activities, such as meal preparation, from caregivers and home-care providers (Brewer-Lowry et al., 2010; Song et al., 2009). Qualitative exploration has also been done regarding older adults' experiences living with UI. Many of the older adult participants did not seek help from health-care providers despite being bothered by UI but had also not been asked about UI by providers (Andersson, Nilsson, Johansson, & Sahlberg-Blom, 2008; Horrocks et al., 2004; Park et al., 2017; White et al., 2014). Thus, participants dealt with UI themselves, sometimes proactively, such as knowing the location of public toilets when out, and often in a potentially harmful manner, for example, not leaving home for fear of public accident (Andersson et al., 2008; Horrocks et al., 2004; Park et al., 2017; White et al., 2014). It is not clear from this research how living with both T2DM and UI is experienced by older adults and how home-care services can support managing both of

these conditions. Experiential knowledge of older adults is needed to inform practice and policy regarding the development of strategies to enhance the detection and management of UI and improve quality of life for older home-care clients with T2DM (Sidani & Braden, 2011). The research question framing this study is: How are T2DM and UI experienced by older adults receiving home-care services?

Method

Interpretive Description Design

This research question was addressed using an interpretive description study design that employed Sally Thorne's (2016) methodology and was part of a convergent, mixed methods research (MMR) study (Northwood, Ploeg, Markle-Reid, & Sherifali, 2019b). The purpose of the larger study was to better understand the complexity of living with T2DM and UI in older adults receiving home-care services. The MMR study also included a qualitative strand exploring how home-care nurses cared for older adults with T2DM and UI (Northwood, Ploeg, Markle-Reid, & Sherifali, 2019c) and a quantitative strand to determine the prevalence and correlates of UI in this population (Northwood et al., 2019a). Grounded in naturalistic and constructivist inquiry, interpretive description is a qualitative research approach that answers clinical practice questions by providing a contextual understanding generated from personal experiences (Thorne, 2016). In addition to its focus on experiential knowledge and human commonalities as well as differences, an interpretive description study produces knowledge that is useful to the disciplines of nursing and other health-care professions (Thorne, 2016).

The study was informed by the complexity model developed by Grembowski and colleagues (2014). In the model, complexity is conceptualized as the disparity between “an individual’s needs and the capacity of the health-care system to support those needs” (Grembowski et al., 2014, p. S10). The degree of this disparity is influenced by contextual factors (i.e., economic and health policies) and the main interacting components in the model: individual characteristics of the person, health and well-being, social supports, the health-care system, and community resources (Grembowski et al., 2014). The model was used to inform study design, develop the interview guide, and inform the initial “sorting and organizing” phase of data analysis in qualitative analysis (Thorne et al., 2016, p. 156). Interpretive description is an appropriate fit for this study because the central goal of this methodology is congruent with the study’s focus: to develop a contextual understanding of the experience of living with T2DM and UI in older adults receiving home-care services (Thorne, 2016).

Researcher Characteristics and Reflexivity

The first author and study lead (MN) is a PhD nursing student with educational preparation and experience in qualitative research and gerontological and continence nursing in home care. The motivation and rationale for studying this topic was related to the lack of a research base to inform nursing and interprofessional practice, and the clinical challenges MN experienced in supporting older home-care clients with diabetes to achieve continence. These challenges included under-treatment of diabetes in older adults that prevented improvements in clients’ continence or urinary symptoms and the lack of coordination of care in the home with clients’ circles of care that spanned multiple

settings, sectors, and providers. The other members of the research team (JP, MMR, DS) are PhD-prepared nurse academics with extensive expertise in qualitative research, mixed methods research, and care of older adults with multimorbidity and diabetes. A reflexive journal kept by MN during data collection and analysis was useful in tracking reflections, challenging initial assumptions, and avoiding premature closure of analysis (Thorne, 2016).

Setting and Sample

Older adult participants were purposively sampled from three of the 14 local health integration networks, the regional agencies that are responsible for the administration of home-care services in Ontario, Canada (Thorne, 2016). Criterion sampling was used in order to ensure all participants met the following inclusion criteria: ≥ 65 years of age, living with T2DM and UI, English-speaking, receiving home-care services, and residing in the community (private home or retirement home; Patton, 2015). The goal was to recruit 15 to 25 older adults to have a large enough sample to detect commonalities and differences and achieve sufficient descriptive depth (Thorne, 2016).

Recruitment occurred from February to July, 2018. Home-care coordinators and nurse participants from the larger MMR study shared informational postcards with their clients. The first author attended community diabetes-education sessions and congregate exercise classes to share information about the study. Study posters were also posted in public locations (e.g., family health team offices, retirement homes, etc.). Potential participants contacted the first author by phone to express interest.

Data Collection

One-on-one interviews—lasting between 60 and 90 minutes—and a short demographic survey were conducted in participants' homes (with one exception where the participant preferred to be interviewed at her adult day program). The interviews were completed by MN using a semi-structured interview guide, informed by the complexity model and current literature, and developed in consultation with the research team. The interview guide is published elsewhere (Northwood et al., 2019b). The first question posed was: Could you describe for me what it is like to have diabetes and incontinence and have home-care services? Questions were also asked about how family caregivers, home-care services, and interactions with the larger health-care system supported the care of their T2DM and UI. Field notes were recorded immediately following each interview, noting contextual details (e.g., home environment) and key concepts or novel information. Interviews were digitally recorded and professionally transcribed.

Data Analysis

Data analysis occurred concurrently with data collection using an inductive and iterative process (Thorne, 2016). The findings were studied to determine the relationship with the complexity model (Bazeley, 2018; Grembowski et al., 2014; Thorne, 2016). The first stages were spent “sorting and organizing” by reading over the transcripts and field notes, sorting data by components of the complexity model, listening to the digital recordings, and noting first impressions (Thorne et al., 2016, p. 156). In the next stages, “making sense of pattern” was completed by applying the qualitative coding strategies of descriptive coding; a label was assigned to describe the topic of a passage of data and

pattern coding, whereby the descriptive codes were grouped together into a smaller number of categories in order to develop themes or groupings (Miles, Huberman, & Saldana, 2014). The relationships between these themes were interrogated, and groupings of data (i.e., subthemes) were moved and/or collapsed (Thorne, 2016). This process was conducted by MN and JP, using a word-processing program and hand coding, and the resultant iterations reviewed by the whole team at four time points. The final stages involved “transforming pattern in findings” through reflection, refinement, and confirming the relationships between the themes and the conclusions to ensure there was not another explanation (Thorne, 2016, p. 173). The research team reviewed and endorsed the final written conceptualization of the findings presented here (Thorne, 2016).

Techniques to Enhance Trustworthiness

The credibility of this study is evidenced by its adherence to the following interpretive description evaluation criteria (Thorne, 2016). First, the study has epistemological integrity as the research team was aware of their shared position regarding the nature of knowledge and disciplinary lens and all study procedures conducted were aligned with that position (Thorne, 2016). Second, representative credibility was achieved by providing a clear description of the study sample, context, and sampling strategy. The analytic logic and interpretive authority of the study is revealed in the detailed descriptions of data collection, data analysis, and findings, following the standards for reporting qualitative research (O’Brien et al., 2014; Thorne,

2016). Also, the provisions for regular team analysis and consensus, along with reflexive journaling, strengthened the interpretive authority of the study.

Ethics

This study received approval from the Hamilton Integrated Ethics Review Board (Project #3024-C) and followed the guidelines stipulated by the Tri-Council Policy Statement (Tri-Council, 2014). Informed, written consent was obtained from all study participants with the understanding that participation in the study would not influence their home-care services. Current or former clients of the first author were not eligible for inclusion. Participants' audio files and transcripts were stored on a password-protected server behind the university's firewall. Transcripts were anonymized of all identifying information (e.g., names of participants).

Results

Description of the Older Adult Participants

A total of 18 older adults with T2DM and UI participated in the study. Most (72%) participants were women who were an average of 75.8 years of age (see Table 1). Most were living with another person (77.8%) and about three-quarters relied on the support of a family caregiver (72.2%). The participants mainly identified themselves as Caucasian (83.2%). More than one half of the sample (55.6%) reported an annual income of <\$40,000, and more than one quarter (27.8%) reported making trade-offs when purchasing essentials, such as home heating or food because of limited income. Participants were also living with impaired mobility and functional limitations; 27.8% of

participants used a wheelchair for mobility, 44.4% used a walker, and 11.1% required a motorized scooter outside of their homes.

Table 1

Demographic and Clinical Characteristics (N=18)

Sociodemographic and Clinical Characteristics	n (%)
Sex	
Female	13 (72.2)
Male	5 (27.8)
Marital status	
Married/Common law	10 (55.6)
Widowed/Separated/Divorced/Never married	8 (44.4)
Ethnicity	
Caucasian	15 (83.2)
Asian	1 (5.6)
South Asian	1 (5.6)
Other	1 (5.6)
Education	
Grade School/none	3 (16.7)
High school/some university or college	10 (55.6)
Trade school/diploma/degree/graduate degree	5 (27.7)
Trade-offs due to limited funds	
Yes	5 (27.8)
No	13 (72.2)
Household Income	
\$39,999 or less	10 (55.6)
>\$40,000	3 (16.7)*
Presence of Caregiver	
Yes	13 (72.2)
No	5 (27.8)
Relationship of Caregiver (n=13)	
Child/Child-in-law	6 (46.1)
Spouse/Partner	5 (38.5)
Other relative/Friend	2 (15.4)
Living Arrangement	
Alone	4 (22.2)
With other(s)	14 (77.8)
Living Setting	
Own home/condominium	9 (50.0)
Rent home/apartment	5 (27.7)
Assisted living	3 (16.7)

Retirement home	1 (5.6)	
Variable	Mean (Standard Deviation)	Range
Age (years)	75.8 (7.7)	66-89
Number of chronic conditions	9.0 (3.1)	4-15
Number of years living with urinary incontinence	7.5 (7.7)	1-20
Number of years living with diabetes	18.4 (12.4)	1-40

Note. *Five participants declined to answer this question.

Older adult study participants had an average of nine chronic conditions in addition to their T2DM, had been living with T2DM for an average of 18.4 years, and with UI for an average of 7.5 years. The most common chronic conditions were: hypertension (83.3%), arthritis (72.2%), osteoporosis (33.3%), kidney disease (27.8%), depression (27.8%), and asthma (27.8%; data not shown). Most participants were taking insulin (66.7%) as part of their treatment for T2DM (data not shown).

More than one half (55.6%) of participants were receiving nursing services, about two thirds (61.1%) were receiving personal support worker (PSW) care, and about one third (33.3%) were receiving both services (data not shown). One quarter (27.8%) of participants were receiving occupational therapy, and 16.7% were receiving physiotherapy (data not shown).

The Experience of Living with Diabetes and Urinary Incontinence for Older Adults Receiving Home-Care Services

The experience of living with T2DM and UI among older adults receiving home-care services is described in the following five themes: (a) enduring urinary incontinence: “patch it in pads”; (b) struggling to manage diabetes, incontinence, and multiple chronic

conditions: “a balancing act”; (c) covering the costs of care: “I can’t afford it”; (d) counting on a caregiver: “he does everything”; and (e) home-care services not meeting my needs: “it’s not individual.”

Enduring urinary incontinence: “Patch it in pads.” Many participants had not received any health-care professional advice on how to manage UI and if they had, they found the treatment offered was not very helpful despite living with UI for an average of 7.5 years. While the older adult participants identified a range of self-care activities that they used to manage their T2DM (i.e., checking their blood sugars, healthy eating, exercising, caring for their feet), they did not feel that they had adequate knowledge and skills to manage their UI. The result is that many endured UI and lived with embarrassment, social isolation, and, for some, serious medical complications.

Many participants disclosed that they had not sought treatment for their UI. Participants did not raise the issue of UI during consultations with their health-care providers regarding their T2DM, and their health care providers did not assess for UI as part of their routine care. For those participants who had consulted health-care professionals regarding their UI, they were not satisfied with the outcome. One female participant had asked her primary-care physician for advice regarding her UI but did not receive treatment: “No suggestions at all regarding that. They don’t know about it” (01). Another female participant expressed concern that she should have received treatment earlier for her UI related to urinary retention:

The only thing I can’t understand is about five years ago I had an examination by a specialist and he said to me then, “You know this is a quart of urine that’s still

left in you, and I know what's wrong, a muscle is gone in you." And he never said anything else, and I keep thinking maybe I should have had something done then? (03)

Other participants described unsuccessful medication treatment for their UI. One male participant explained, "I think what was in that bottle, you're either lucky or not, because sometimes I take them and it worked perfect. Sometimes I'd take them, they don't do nothing. Out of the same bottle" (17).

Only a few participants were aware of the relationship between T2DM and UI. One female participant referred to the relationship of diabetes and UI as "cousins" and explained, "Well, of course I have to control my sugar, because apparently when the sugar gets high it makes a bladder infection" (03). The most common way that participants coped with UI was by wearing incontinence products, such as pull-ups or pads. "Just patch it in pads," one discouraged female participant remarked about how she managed her UI (01). Living with UI involved resignation by the participants that this condition could not be treated, as described by this male participant: "Because most of the time you're just not close enough to a bathroom to make it in time, but I learned to live with that. So, I buy protective undergarments in bulk" (18). Only a few participants mentioned continence promotion strategies, such as maintaining a healthy clear fluid intake and avoiding caffeine.

Participants indicated that living with UI was upsetting, embarrassing, socially isolating, and, for some, contributed to serious complications. Participants divulged that leaving home was challenging due to frequent urination or the need for assistance in toileting and changing incontinence products. This participant frustratingly shared:

The worst thing is if we're going to go out, we've got an appointment or something. I've gone to toilet, and then I come through the house, and I've got an elevator in the garage, and I go down, and I go sit in the car and I dribble. And it comes out. Hate it. Absolutely hate it. So, then I have to go all the way back in. (02)

Another participant dreaded going out in public as she had to void so frequently: "When you have to get up and go and the church service is on, like that part I don't like" (07).

Another participant also shared her embarrassment and fear of a public accident:

The thing that I'm more scared of if this happens to me outside of the home. I'm always worrying, "am I going to pee myself, now?" And always when I go in the store or somewhere that I don't know, I always ask "where is the washroom?" (10)

Living with UI contributed to serious health crises for some participants, such as hospitalizations for urinary sepsis and delirium, and visits to the emergency department for recurrent urinary tract infections. A female participant reported still being bothered by memories of delirium when she had been hospitalized with urinary sepsis: "I swore for a long time that I was dropped from a gurney and was unconscious because I hit my head. My son found no proof of that fact. And I think it was one of my hallucinations" (01). In summary, most participants had not received treatment to address their UI and were left to manage UI on their own.

Struggling to manage diabetes, incontinence, and multiple chronic conditions: "A balancing act." Participants were also managing many other chronic conditions (average of nine) along with their UI and T2DM. As one female participant exclaimed, "Almost every part of my body has a problem!" (05). This translated into challenges receiving treatment for UI. Additionally, having MCC created problems managing their incontinence. The negative impact of struggling to manage self-care for

all their chronic conditions meant that these participants had to be intentional about attending to their emotional and social health.

Many participants had interactions with all parts of the health-care system—primary, specialist, acute, and emergency care—to address their MCC. In these many interactions, they often found that the treatment being offered for their UI either conflicted with treatments they were receiving for their other chronic conditions or was not geared to their individual needs and abilities. A female participant who had urinary retention and was receiving daily nursing visits described how the home-care nurses tried to teach her intermittent self-catheterization:

I know they say you can stand up [to pass catheter], well I haven't got great balance now, you know? And one said, put your leg on the side of the bathtub. I can just see me, there would be a broken hip here. (03)

She understood from the nurses that they would not be able to continue visits indefinitely and, as such, the only remaining alternative would be to wear an indwelling catheter, which was an enormous worry and source of distress for this participant. Conversely, another participant wanted to have an indwelling catheter to manage her UI, due to the development of a pressure injury and worsening mobility but was declined that treatment by a specialist. Her husband described that appointment:

We got there and they asked [Participant] to get on the table and she peed all over the floor. Well she's incontinent. They had her pull-ups off. So of course, where is it going to go? So I stepped in, I said "She needs a catheter." And then the doctor said "No, no, we don't do catheters here," and I knew then she wasn't the right doctor for [Participant]. She's supposed to be an incontinence doctor. (04)

Another participant consulted a urologist regarding her UI and was advised that she would benefit from surgery, but she was not a candidate because of “problems” from her T2DM (10). No other treatment options were offered.

For this participant, living with her other chronic conditions made the management of UI feel overwhelming: “The incontinence was just more like the icing on the cake. It was just one more thing I couldn’t handle” (06). A female participant with both congestive heart failure and recurrent urinary tract infections described the careful vigilance she kept balancing the treatment for one condition (diuresis) with the other (hydration):

I drink lots of water. However, with the congestive heart failure, sometimes I have too much fluid that accumulates around my heart, so they give me an extra diuretic to get rid of it. But then the urine gets too strong. And so, you know, it’s really a balancing act. I keep a very close watch on my feet, make sure they’re not swelling. And I can tell, my mouth gets dry if I’m too dehydrated. But it’s really hard. (13)

Participants often reported using exercise as a strategy to keep well with T2DM, UI, and MCC. A few participants had the advantage of attending an adult day program where they had formal exercise plans, including a stationary bike customized for poor limb control. Another participant regularly attended a class in his building: “I try to move but the little exercise class downstairs is saving my life” (11). Other participants wanted to be able to exercise but pain or shortness of breath prevented them from participating in exercise classes. This participant disclosed her disappointment about not being able to swim any longer: “I went to the pool. But, I suddenly acquired this incontinent bowel and it just didn’t work anymore” (12).

The experience of living with T2DM, UI, and MCC involved striking a balance between bothersome symptoms and maintenance of a social life inclusive of opportunities for joy. Participants shared how having fun was an integral part of their self-care and self-image. A female participant emphasized the positive social aspect of her community day program: “It’s a social thing. I go for the exercise, number one. But it’s social. It’s getting me out of the house, it’s getting me with other people. I’ve made some really good friends” (06). Another participant, who lived in a retirement home, stressed the importance of being social and how engaging co-residents to participate in group activities was also a benefit for her. Thus, the participants struggled to find a balance between the treatments being offered and their individual needs and preferences.

Covering the costs of care: “I can’t afford it.” Participants indicated that the costs associated with managing their T2DM and UI were challenging. There were multiple out-of-pocket expenses that were not publicly funded, including incontinence products and T2DM supplies, attending adult day programs, and supplementing home-care services.

Older adult participants noted that incontinence products were very costly, especially when living on a fixed income, as this female participant shared: “It was pretty bad. We were going through 70, 80 bucks a week in pull-ups” (06). T2DM supplies are only partially covered by the provincial government, requiring this participant to make trade-offs using her insulin pen. She explained, “They say you should change your needle every time you use it. I don’t because needles are too expensive. I use mine more than once” (16).

For many participants, attending adult day programs was one of their self-care activities, but they were not attending as often as they would like due to the financial impact. This female participant divulged, “I would like to go another day but I can’t afford it, I mean I know it’s only \$6 a day but it adds up. And I don’t eat there, I usually take my own lunch because that’s [another] \$6.50” (02).

A few participants had out-of-pocket expenditures for home-care services that they required. For example, one participant wanted assistance with housekeeping for which he was deemed ineligible, but he could not afford a cleaning service. He shared, “To sweep or mop the floor is a huge [effort], I can’t afford a cleaning service to come in and clean the bathroom and wash the floors. As you can see, my carpet’s gotten a terrible mess” (18). Another participant with low vision required the support of a PSW to accompany her to appointments, so she paid for private help. One participant was uncertain how long the daily nursing service she was receiving for intermittent catheterization would continue: “I have to wait until they tell me you can’t have it anymore because I know I can’t afford to pay for it” (03). Participants had needs for services and supplies in order to remain in their own homes that fell outside of what was covered through publicly funded home care and had to pay the high costs associated with these expenses.

Counting on a caregiver: “He does everything.” Many participants were dependent on the support of caregivers to remain at home, manage T2DM and UI, and shared stories of the tremendous burden this placed on caregivers. Some participants

were caregivers to a spouse and discussed the negative impact caregiving had on their health and well-being.

Family caregivers provided important instrumental support to the participants, including, but not limited to, bathing, dressing, driving, cooking, cleaning, grocery shopping, and social support. As one participant summarized of her husband: “He helps me with everything” (09). After sustaining a brain injury, another participant moved in with her sister: “I’m really thankful that [sister] had asked me to come and stay. It’s really helped me” (07). Another participant talked about how important her son was in helping her stay in her own home: “He does everything. He cooks, he bakes” (08). In contrast, most of the male participants did not have the benefit of caregiver support as they were divorced and living alone.

This level of support did come at a cost for some of the participants’ caregivers. Several female participants indicated that they were concerned about the impact of caregiving on their spouses. One participant angrily described a time when the home-care coordinator attempted to reduce her PSW services: “I said to that case manager, I said ‘What do you want to do? Run him ragged so he has a total break down and he’s no good to no one? What you going to do then?’” (02). Another participant, whose husband worked full-time, worried about his sleep given her need for nighttime toileting support: “If he’s home, he do everything. Two time in the night he get up. I go pee two time in the night. What I can do?” (09). A participant on a wait-list for PSW services disclosed her concerns about the negative impact of caregiving on her relationship with her husband:

He helps me with my showers and that's why we wanted the PSW because he still works full-time. So, I wanted something that eases up some time for him, you know. Just someone to help me shower. I can't manage it on my own. I would like to be able to get up and have a shower in the morning. Just to do it without—I think I'm going to cry—without him having to do it, you know. You don't want your husband doing everything for you. (06)

This participant also felt that the assessment completed by the home-care coordinator to determine service eligibility did not consider if her husband was experiencing distress as a caregiver; the process only assessed if a caregiver was present in the home.

Other participants were providing care to family while coping with their own health issues. One participant daily visited her sister who was living with dementia. Another participant shared the challenges of supporting her husband with dementia, who had previously been responsible for their finances and some cooking: “He cannot help me. Before he was doing a little bit, cutting the vegetables and all that. He cannot turn on the toaster, I am scared. Best he leave it. Sometimes he left food out overnight” (05). A participant shared how concerned he was for his wife during his hospitalization: “When I came down with a bad kidney disease, I was in the hospital just over two months and she was home alone. She's all crippled up, she can't get up by herself. So she had a pretty tough time” (11). He also shared that he wished that the PSWs who cared for his wife provided support to him as her caregiver: “They do everything for [wife], okay, to my point of thinking, they kind of ignore me” (11). Thus, care for the caregiver was not part of home-care services for these participants, adding to the complexity of living with UI, T2DM, and MCC.

Home-care services not meeting my needs: “It’s not individual.” Participants indicated that the home-care services they were receiving did not always meet their individual needs, including navigating the larger health-care system.

During this participant’s assessment for home-care services, she felt that her unique needs and family situation were not considered:

It’s not individual at all. It was just, “Can you do this?” and “Can you not do this?” and “Who can do it for you?” They ask, “Could your daughter do anything for you?” Well, my daughter works in [City A] and lives in [City B] and has two little boys. She doesn’t have time to be coming over and doing stuff for mom. They’re not listening to that aspect that’s under the surface. It’s all cut and dry and black and white. (06)

She had also been waiting for months for her PSW services to begin. She shared, “They tell you that they want you out of hospital and we’re going to provide all this help for you, and there’s no help. I just wish the whole process was easier to get on the wheel” (06). Another participant was deemed ineligible for PSW services even though he needed help with meal preparation (due to pain and fatigue on standing). He stated with resignation, “The government doesn’t cover the cost of them doing that” (18).

Participants indicated that they had unmet needs with respect to support from PSWs. For example, one participant wanted more help with meal preparation, and another with housekeeping. However, due to time constraints, the PSWs could only provide these services if they had time after attending to personal care. Another participant had to adjust her meals and medications around the availability of PSWs as she required a mechanical lifter to get out of bed, which had a negative impact on the management of her T2DM. She explained, “They get me up at 11:00 in the morning, so

my needles are not, you know, regular breakfast, lunch, and dinner things” (13). Having the same PSW who they knew and trusted was also important to participants, but this was not always provided. They described feeling uncertain around “strangers” and it was challenging to explain to a new PSW all the nuances of the care they required (05). This male participant, receiving twice-daily PSW support, experienced difficulties with unfamiliar PSWs:

They send people who don’t know what they’re doing, they haven’t got a clue of how to put a catheter [bag] on. So, they sit there with the plug and they’re wondering which end should they stick it in. Well, a lot of times I have to depend on her [wife], her nurses fix it the right way. (14)

When asked about the care that nurses provided during their home visits, participants described the tasks that they completed, such as wound care, intermittent catheterization, intravenous medication delivery, and indwelling catheter insertion. When asked directly if the participants had discussed management of T2DM and/or UI with the home-care nurses, most replied they had not: “We just deal with the wounds and that. Because I never get the same one [home-care nurse] twice,” stated one male participant (15).

Participants indicated that they experienced challenges accessing health-care and community-support services. Participants described how they received limited information about services in the community from their home-care providers. Rather, they often found out about community services on their own, stumbling upon programs that were beneficial to their health instead of learning of these programs from a health-care professional (i.e., home-care coordinator). For example, a few female participants

explained that they self-referred to a nurse-led outpatient continence clinic after seeing a poster in the hospital. A male participant found out about the adult day program he was attending after seeing a poster in a church. Another participant learned about her adult day program from her daughter who, living out-of-town, conducted an online search for programs that could support her mother.

In contrast, however, some participants described situations where the home-care services provided did meet their needs. Participants described the many ways that PSWs enriched their lives and their health. This participant remarked fondly of his primary PSWs, “At this stage of the game, they’re like part of the family” (14). Participants expressed gratitude for support with bathing, dressing, laundry, medication reminders, meals, and light housekeeping. One female participant’s PSW also identified the development of a new pressure injury and advocated for timely nursing treatment. Another female participant detailed how her primary PSW was also attuned to changes in her health:

The one that I’ve had on a regular basis, she makes sure I get breakfast because she knows that I have not been totally right. So, this morning she cooked me two eggs and when she’s leaving, “You eat it, don’t just leave it there.” (16)

A few participants lived in assisted-living buildings with on-site PSW access through a personal-alert system and found this arrangement exceptional for regularly scheduled care provision and the security of knowing PSWs could be summoned in emergency situations, such as falls.

There were also a few notable exceptions when participants received more holistic nursing care. One female participant had received diabetes education regarding

nutrition and blood glucose monitoring from a home-care nurse when she was first diagnosed with T2DM. Also, two participants received helpful education regarding incontinence products, performing pelvic floor muscle exercises, and managing vaginal prolapse during home visits from a previous nurse continence advisor. One shared that the home-care nurse continence advisor "... was very helpful and, you know, talked about the exercises and many, many areas that she helped me in" (06).

Discussion

To our knowledge, this is the first study to explore the experiences of older adults with T2DM and UI receiving home-care services. In summary, participants endured UI and, for the most part, did not ask for and were not offered acceptable treatment. The ability of this population to continue to live at home in the community was threatened by a number of factors, including care that was incongruent with participants' goals, needs, and MCC; difficulties affording costly supplies and services; and the lack of health-care-professional-led navigation through the larger health-care system. Receiving home care that promoted aging-in-place occurred when home-care service providers were able to meet the unique needs of each participant in an enriching and enabling manner. These study findings have generated several key contributions to the knowledge regarding how older adults receiving home care experience living with T2DM and UI.

First, a concerning finding is the resignation of participants to the belief that UI was a condition that must be endured. As well, despite contact with multiple health-care providers in different settings, UI was not detected and consequently treatment for UI was not consistently provided and participants lacked knowledge and self-care skills to

manage UI. The finding that older adults are not routinely assessed for UI, and older adults do not routinely ask health-care professionals for advice on managing UI is congruent with other qualitative research involving community-dwelling older adults (Andersson et al., 2008; White et al., 2014). This current study affirms that this unfortunately remains true even for older adults accessing home-care services. Yet, a process is in place in Ontario to identify older adults receiving home care who would benefit from interventions to improve bladder function or prevent worsening of UI (Morris et al., 2008). Home-care coordinators conduct a standardized assessment, the Resident Assessment Instrument for Home Care, from which one of the outputs is the UI clinical assessment protocol which should trigger the home-care coordinator to develop a care and service plan.

Second, living with T2DM and UI involves a challenging self-care regimen for home-care recipients. This finding is consistent with the qualitative literature regarding self-management of T2DM for older adults (Carolan-Olah & Cassar, 2018; Joo & Lee, 2016; Song et al., 2009). The careful balancing that participants described in managing their chronic conditions is commonly reported in the MCC literature (Boyd & Fortin, 2010). For example, that treatment for one condition (e.g., diuresis) worsens another condition (e.g., incontinence), or a treatment (e.g., exercise for weight loss in a person with diabetes) is not feasible due to complications related to another condition (e.g., shortness of breath in chronic obstructive lung disease (Boyd & Fortin, 2010; Grembowski et al., 2014)). What this study highlighted is the importance of considering MCC in the treatment of UI for older home-care recipients with T2DM. For example,

“prescribing fun”—such as engaging with an adult day program—would not be included in best practice guidelines for managing UI but could be protective against the depression and functional decline that is associated with T2DM and UI in older adults (Coll-Planas, Denkinger, & Nikolaus, 2008; Dugan et al., 2000; Meneilly et al., 2018; Wagg et al., 2016).

Third, the finding that inadequate financial resources negatively affected older adults living with T2DM and UI is noteworthy. This highlights the role of the social determinants of health on the management of chronic conditions (Grembowski et al., 2014). Other research has noted socioeconomic disparities in diabetes care: namely that adults with diabetes in the lowest household income group in Canada do not receive all types of recommended care and have higher hospitalization rates than those in a higher income group (CIHI, 2009). Qualitative research with adults with diabetes and low income also found that it was a “daily struggle” to manage both diabetes and the adversities of living with limited funds (Pilkington et al., 2010, p. 122). The Canadian Continence Foundation (CCF) has identified the economic impact of UI and estimates that an individual with UI spends \$2,100 on incontinence supplies per year (CCF, 2014). Unfortunately, provincial government funding is not presently available for incontinence products. Conceptualizations of MCC in the research literature often fail to acknowledge the impact of socioeconomic status on the experiences of older adults but this study underscores the importance of recognizing and addressing potential health disparities related to income (Northwood et al., 2017).

Fourth, caregivers report significant levels of burden in supporting older adults with T2DM and UI. The negative impact of UI on older adult caregivers in terms of role changes, sleeping issues, and emotional responses has been previously reported (Cassells & Watt, 2003). Recent reports on home care in Canada emphasize the need to engage caregivers as partners in care and support them in their roles (BHCCP, 2016). A troubling finding in this study was that caregiver burden existed even in the presence of home-care service provision. Also, caregiver presence, rather than ability and willingness to perform care activities, was a deciding factor in how much home-care service was provided. Engagement and support of caregivers is important for caregiver well-being and that of their dependent care recipients, especially since UI is a potentially modifiable predictor of long-term care placement (Wagg et al., 2016).

Finally, many participants living with T2DM and UI reported unmet needs. Participants shared that the home-care services they were receiving did not meet their needs, thus threatening their ability to successfully age-in-place. However, participants also shared instances where home-care support was optimal: receiving nursing support and education for T2DM and UI, developing relationships over time with PSWs, and assisted-living models with access to on-call support. These findings highlight that, despite examples of excellence, at the system level there are ongoing and significant barriers to patient- and family-centred home-care provision for this population in Ontario.

Implications

These findings have several implications for clinical practice. To start, given that participants shared that home-care services were not meeting their individual needs, care for this population would be enhanced by taking a person- and family-centred approach to service provision and care coordination (BHCCP, 2016). As well, acknowledging and mitigating the financial burden of uncovered costs is an important consideration for this population. Thus, home-care providers should intervene to address poverty by directing older adults to free community services to help with income tax filing, thereby ensuring that all potential sources of government funding are optimized (Jones, Bloch, & Pinto, 2017). Also, the clinical management of T2DM and UI must be considered in the context of MCC. The clinical complexity of a home-care population of older adults warrants special mention in clinical practice guidelines for diabetes management, like those for the long-term care population (Meneilly et al., 2018). The results underscore the need for routine screening for UI in older home-care clients during diabetes consultations. Conversely, while clinical practice guidelines for UI typically include the assessment of conditions known to be associated with UI (i.e., diabetes), the impact of MCC should also be included with reference to guidelines for care of older adults with MCC (Vetrano et al., 2018). Community support services, such as adult day programs, provided much needed socialization and exercise to this group of older adults with complex needs, and as such, should be part of the services that are discussed with home-care clients.

From a policy perspective, urgent attention is required to add incontinence products to the special supplies covered by Ontario's Assistive Devices Program for older

adults with low income. As well, home care eligibility criteria should be expanded to include services and supports for family and friend caregiver support (BHCCP, 2016; Northwood et al., 2017).

Future research is required to design and test a person- and family-centred approach to managing UI in home-care clients with T2DM and MCC. The barriers to implementing such a plan (e.g., home-care resources, policies, and the knowledge of home-care service providers on managing UI in the context of MCC) require further research exploration. Also, a review of the use of the Resident Assessment Instrument for Home Care UI clinical assessment protocol to inform service delivery is needed to optimize existing processes for care planning. Finally, an investigation of the perspectives of ethnoculturally diverse home-care recipients is needed.

Study Strengths and Limitations

The study's main strength was the thoughtful adherence to the principles of interpretive description methodology and the participation of a team of researchers in analysis and articulation of the final conceptualization of the findings. In addition, the participants varied by types of chronic conditions and were recruited from three different regional home-care programs of urban and rural geography. The findings likely have transferability to other provincial home-care programs as well as other countries with publicly funded health care. The complexity model was very useful in informing the interview guide and analysis as it ensured that a broad range of potential factors affecting older adults with MCC were considered (Grembowski et al., 2014). The main study limitation was the lack of ethnocultural diversity in the study sample. Additionally, as

fewer men than women were recruited to the study, we were not able to examine the findings for sex and gender differences. Only 10 participants received nursing care and so it is likely that the inclusion of more participant experiences with home-care nurses would have further enhanced our understanding of implications for nursing practice.

Conclusion

Older adults with UI and T2DM receiving home-care services are also living with MCC. They do not consistently receive home-care services that consider: their unique needs; the complex interplay of UI, T2DM, and MCC; and other contributing factors to UI, such as limited finances and caregiver burden. A holistic approach—including routine screening for UI, managing UI and diabetes in the context of MCC, and attention to the social determinants of health—is needed to improve the quality of life for this population.

Conflict of Interest

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CHAPTER SIX

TITLE: Home-care nurses' experiences of caring for older adults with type 2 diabetes mellitus and urinary incontinence: An interpretive description study

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Abstract

Background: A third (33.7%) of older adults with diabetes receiving home-care services have daily urinary incontinence, and many of these individuals have multiple chronic conditions (\geq two chronic conditions). Diabetes, urinary incontinence, and multiple chronic conditions in older adults are associated with poorer functional status and lower quality of life. Home-care nurses have the potential to play an important role in supporting older adults in the management of these conditions. However, very little is known about home-care nurses' experiences providing care to this population.

Objective: The objective of this study was to explore how nurses care for older adults with diabetes, incontinence, and multiple chronic conditions.

Design: This was an interpretive description study informed by a model of clinical complexity, and part of a larger convergent, mixed methods research study.

Method: Fifteen nurse participants were purposively recruited from home-care programs in southern Ontario, Canada to participate in semi-structured qualitative interviews. An interpretive description analytical process was used to examine the interview data that involved constant comparative analysis and attention to commonalities and variance.

Results: The experiences of home-care nurses caring for this population of older adults was described in three themes and associated subthemes: (a) conducting a comprehensive nursing assessment with client and caregiver, (b) providing holistic treatment for multiple chronic conditions, and (c) collaborating with the interprofessional team.

Conclusions: The results suggest that interventions for older adults with diabetes and incontinence should pay attention to the broader social determinants of health in the context of multiple chronic conditions. The results can be used to inform the design of a nursing intervention to promote continence and support diabetes management for older adults with multiple chronic conditions.

Home-care nurses' experiences of caring for older adults with type 2 diabetes mellitus
and urinary incontinence: An interpretive description study

Introduction

Urinary incontinence (UI) is a prevalent problem internationally for older adults living with type 2 diabetes mellitus (T2DM) who receive home-care services (Hsu et al., 2014; Vetrano et al., 2016). UI in older adults (aged ≥ 65 years) is associated with many negative outcomes, such as falls, fractures, anxiety, depression, reduced quality of life, and premature institutionalization (Hsu et al., 2014; Coyne et al., 2013; Wagg et al., 2017). A cross-sectional study of older adults with T2DM receiving home-care services in Ontario, Canada, found that 33.7% experienced daily UI (Northwood et al., 2019a). The majority (90%) of older adults with T2DM receiving home-care services are also living with multiple chronic conditions (MCC; ≥ 2 chronic conditions), which contributes to poorer diabetes self-management and increased health-care utilization (Gruneir et al., 2016). Home-care programs internationally are supporting older clients with increasingly complex health- and social-care needs (Canadian Institute for Health Information, 2018; Martinsen, Mortensen, & Norlyk, 2018).

Home-care nurses have the potential to play an important role in supporting older adults in managing their UI (Community Health Nurses of Canada, 2011). No research was located on how home-care nurses care for older adults with T2DM and UI. Three studies were found that described the experiences of home-care nurses caring for older adults living with diabetes (Fox et al., 2006; Gifford et al., 2013; Kolltveit et al., 2017). Home-care nurses' in these studies experienced many barriers to caring for older adults

with diabetes, such as limited access to other home-care providers (i.e., registered dietitians or specialty diabetes educators), lack of formal collaboration with primary care, and clients' social, mental, and physical concerns that needed management in addition to providing diabetes care (Fox et al., 2006; Gifford et al., 2013; Kolltveit et al., 2017). Only one study was found regarding home-care nurses' experiences caring for older adults with UI (Jansen et al., 2013). In this grounded theory study of home-care providers' knowledge translation related to UI, nurse participants focused on developing a relationship with the client and their caregiver but did not describe sharing continence-promoting knowledge (Jansen et al., 2013).

Thus, little is known about how nurses care for older adults with T2DM and UI. Understanding the subjective experiences of nurses is an important part of intervention development to clarify the clinical problem and identify effective strategies to mitigate the problem as well as gaps in service delivery (Sidani & Braden, 2011). This study will address this gap in knowledge and create a much-needed evidence base to inform home-care nursing practice, policy, and future research. The research question for this study was: How do home-care nurses care for older adults with T2DM and UI?

Methods

Study Design

This research question was addressed using an interpretive description methodology. The first author and study lead (MN) is a PhD student and home-care nurse. The impetus for exploring this topic was related to a lack of research evidence to inform best practice nursing interventions for this population and the very challenging

clinical dilemmas experienced by MN in supporting older home-care clients with T2DM to achieve continence. These challenges included the lack of health-care providers' knowledge of the relationship between T2DM and UI in older adults and the subsequent under-treatment of UI as well as barriers to coordinating care between home, specialist, and primary care.

This study was part of a convergent, mixed methods research study with the aim of better understanding the complexity of living with T2DM and UI in older adults receiving home-care services (Creswell & Plano Clark, 2018; Northwood, Ploeg, Markle-Reid, & Sherfiali, 2019b). The mixed methods study also involved a qualitative exploration of the experiences of older adults with T2DM and UI receiving home-care services (Northwood, Ploeg, Markle-Reid, & Sherfiali, 2019c) and a quantitative strand to determine the prevalence and correlates of UI in this population (Northwood et al., 2019a). Interpretive description is an applied health research approach that identifies a knowledge-practice gap and gathers knowledge to achieve a contextual understanding of the commonalities and differences of persons experiencing the phenomena in question (Thorne, 2016). Nurses, by virtue of their clinical experiences and observations of many older adults with both T2DM and UI, provide the “thoughtful clinician” perspective and can provide rich insights into this population and the care they require (Thorne, 2016, p. 93).

A model of complexity for persons with MCC was used to inform study design, develop the interview guide, and inform the initial phase of analysis (Grembowski et al., 2014; Thorne, 2016). This model of complexity was chosen as it considers many factors

that lie outside of the health-care system affecting older adults' health and well-being, such as community services and social support (Zullig et al., 2015). Clinical complexity is influenced by the capacity of the health-care system to meet clients' needs based on their individual characteristics, health and well-being, and social supports as well as contextual health, economic, and social policies that create health disparities (Grembowski et al., 2014).

Setting and Sampling

Nurse participants were purposively sampled from three Local Health Integration Networks (LHINs), the regional organizations that are responsible for administration of home-care services in Ontario, Canada. LHINs employ care coordinators who assess client eligibility for services and monitor and adjust their service plans over time. The care coordinators organize access to contracted services—such as nursing or personal support—from multiple service provider agencies. Maximum variation sampling was used to ensure diversity in role (e.g., continence specialist), professional registration class (e.g., registered nurse), and length of experience in home care among the study participants (Patton, 2015). Participants met the following inclusion criteria: licensed as registered nurses (general or extended class) or registered practical nurses; practiced in home care for at least six months; and cared for older adults with T2DM, UI, and MCC. Recruitment occurred from July 2017 to May 2018. Nurses were recruited through one service provider's electronic newsletter and one of the authors emailed nurses in her professional network informing them of the study.

Data Collection

Interviews were conducted over the phone or in-person at a location of the participants' choosing (e.g., office). The interviews were completed by MN using a semi-structured interview guide beginning with the grand-tour question: "Can you tell me about how you approach the care of an older adult that has both diabetes and incontinence?" (Spradley, 1979). The interview guide, published previously, was informed by research evidence and contained questions to address each of the components of the complexity model (Grembowski et al., 2014; Northwood et al., 2019b). Sociodemographic characteristics were also captured using a short demographic survey. The interviews were digitally recorded and transcribed verbatim. Field notes were recorded immediately after each interview, noting contextual details and key concepts to address in subsequent interviews. Recruitment ended when the authors felt they could reasonably conclude that enough experiences were obtained in order to generate a credible interpretive description (Thorne, 2016).

Data Analysis

Data analysis occurred concurrently with data collection using an inductive and iterative process (refer to Table 1). The interpretive description analytical process involved constant comparative analysis, reflexive journaling, attention to commonalities and variance, and research team discussion (Thorne, 2016). The first two phases of the analysis process were conducted by MN and JP, utilizing both handwritten coding and a word-processing program to describe and rework codes into themes. During the early "sorting and organizing" phase, the components of the complexity model were used to

organize the data (Grembowski et al., 2014; Thorne, 2016; p. 156). The thematic outputs were discussed with all authors at four time points and culminated in the third stage of “transforming the pattern in findings” (Thorne, 2016, p. 173). The audit trail was shared at meetings, showing the development of sorting the data, the coding scheme and associated quotes, interpretative themes, and reflections from journaling (Thorne, 2016). Further analysis and refinement of the written conceptualization continued with input from all authors to produce these final written results.

Table 1

Interpretive Description Process of Analysis

(1) “Sorting and organizing” by reading and re-reading transcripts and field notes, listening to digital recordings, sorting data by components of the complexity model, journaling preliminary thoughts.
(2) “Making sense of pattern” by applying descriptive codes to segments of the transcripts and pattern codes to group together descriptive codes into larger themes
(3) “Transforming pattern in findings” by testing relationships of themes to emerging conclusions and ensuring no other explanation
(4) Writing conceptualization of the findings

Note. Adapted from Thorne (2016).

Trustworthiness

To ensure trustworthiness, credibility processes were built into the study design (Thorne, 2016). First, sampling included diverse participants. Second, these qualitative results were reported in adherence to COREQ criteria (Tong, Sainsbury, & Craig, 2007). Third, the research team had expertise in qualitative research, mixed methods research, and nursing intervention research with older adults, caregivers, and persons with diabetes.

Ethical Considerations

This study was approved by the Hamilton Integrated Ethics Review Board (project #3024-C) and followed the guidelines of the Tri-Council Policy on the ethical conduct of research (Tri-Council, 2014). Informed, written consent or verbal consent (for phone interviews) was obtained from all participants prior to conducting the interviews. Participants' privacy and confidentiality was guarded by password protecting and storing all digitally recorded interviews and transcripts on a password protected server, and anonymizing the transcripts of identifying information (e.g., names and locations).

Findings

Description of the Nurse Participants

Fifteen nurses participated in the interviews (nine registered nurses, one nurse practitioner, and five registered practical nurses; see Table 2). Almost all (93%) of the participants were female and were an average of 54 years of age. Almost two thirds (66.7%) of study participants had more than 16 years of clinical experience and over one half (50%) had more than 11 years' experience working in home care specifically. Forty percent of participants had completed formal education as a nurse continence advisor, and 13.3% had completed specialized education in wound, ostomy, and continence care.

Table 2

Nurse Participants' Demographic Characteristics (N=15)

Variable	n (%)
Gender	
Male	1 (6.7)
Female	14 (93.3)
Education	

Variable	n (%)
Diploma	9 (60.0)
Bachelor's degree	5 (33.3)
Master's degree	1 (6.7)
Registration	
Registered Nurse	9 (60.0)
Registered Practical Nurse	5 (33.3)
Nurse Practitioner	1 (6.7)
Certificate	
Nurse Continence Advisor	6 (40.0)
Nurse Specialized in Wound, Ostomy and Continence	2 (13.3)
None	7 (46.7)
Years in Practice	
6-10	3 (20.0)
11-15	2 (13.3)
16-20	1 (6.7)
20+	9 (60.0)
Years in Home Care	
1-5	3 (20.0)
6-10	4 (26.7)
11-15	2 (13.3)
16-20	4 (26.7)
20+	2 (13.3)
	Mean (Standard Deviation)
Age	53.8 (13.7)

Home-Care Nurses' Care of Older Adults with Diabetes and Urinary Incontinence

Three main themes and associated subthemes emerged regarding how home-care nurses cared for older adults with T2DM and UI: (a) conducting a comprehensive nursing assessment with client and caregiver, (b) providing holistic treatment for MCC, and (c) collaborating with the interprofessional team (see Figure 1).

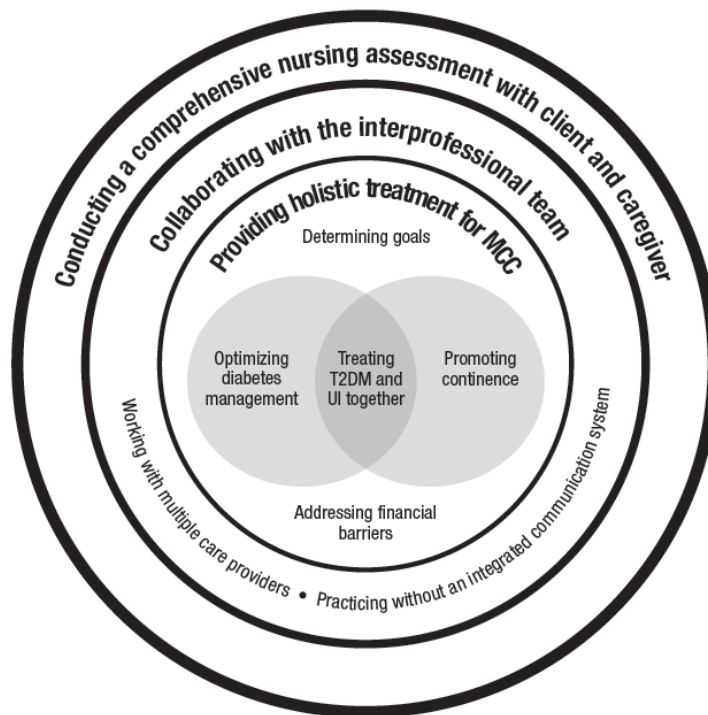


Figure 1. Thematic Conceptualization of the Findings.

Conducting a comprehensive nursing assessment with client and caregiver.

Participants described that the first step in caring for older clients with T2DM and UI and their caregivers was to conduct a comprehensive nursing assessment. They revealed that the contributing factors to T2DM and UI management were quite complex owing to the presence of MCC. As this participant detailed:

A lot of people with diabetes also are obese, high blood pressure, their blood sugars are kind of not in control, peripheral edema, and neuropathy affecting their bladder and decreased mobility. Like there's just so many contributing factors than besides being, let's say, an older woman with five kids. People with diabetes have so many other contributing factors that they are very complex patients. (03)

As a result, nurse participants not only collected a history related to T2DM and UI but also on their other chronic conditions, geriatric syndromes (e.g., falls), and self-management abilities: “You have to do a comprehensive assessment first before you make any recommendations including their functional abilities, cognitive deficit, mental health issues, social supports, of course, the impact of incontinence on quality of life to determine your approach” (02). Nurses also reported collecting information on medications, falls, involvement of specialists, loneliness, diet, and fecal incontinence. The participants shared that many of their clients had some degree of cognitive impairment that may or may not be formally diagnosed and this was important for nurses to ascertain as their care would have to be tailored to accommodate memory impairment. This nurse explained:

When there is cognitive impairment involved, then we need to work more with the people that are around that patient and we need to assess as to what degree does this patient receive support in order to be able to function in the community independently or semi-independently. (01)

Nurses evaluated the home environment for condition of the home (i.e., disrepair, safety), food security, and distance to the bathroom. Being in the home afforded the nurses key insights, as this participant described:

Because in community nursing, you’re in there, you see that there’s only a chunk of cheese in the fridge or that they can’t get from their bathroom to their chair without leaking because they’re going up three flights of stairs. (09)

Nurse participants indicated that they also assessed the needs of caregivers of the older adults with diabetes and UI. This helped them to determine what support they were providing to older adults, such as maintaining hygiene or seeking health care, and the

kind of support that they needed. As well, nurse participants identified the impact of caregiver burden (e.g., sleeplessness, frustration) and planned strategies to lessen their caregiving duties (e.g., respite services). The nurse participants regarded supporting caregivers in managing UI to be of the utmost importance in facilitating aging-in-place, as described by this nurse: “And a lot of them will talk about placement, because they can’t handle the urinary incontinence or bowel incontinence” (09).

Participants also assessed areas specific to T2DM self-management (e.g., blood glucose monitoring, using medications as directed, making healthy food choices). Nurse continence advisor participants determined the relationship between hyperglycemia and UI and the client’s perceptions regarding this relationship, as well as standard UI assessment components (e.g., fluid intake, voiding frequency, physical assessment). A notable exception was raised by nurses specializing in wound care, who shared that incontinence was not part of their standardized home-care assessment: “I leave it to the patient to bring it to my attention” (NP10).

Providing holistic treatment for MCC. Nurse participants identified several strategies—starting with determining goals with the client and caregiver—that they used to manage T2DM and UI, recognizing the interplay between T2DM and UI and the influence of MCC. Some of these strategies improved both T2DM and UI simultaneously, some addressed broader concerns (i.e., financial barriers), and others targeted each condition separately. The nurses indicated that they worked diligently to try to provide holistic care however, they faced several barriers.

Determining goals. The nurse participants took a pragmatic approach to determining goals for treatment with older adults and their caregivers. They described establishing what bothered the client most and what could realistically be improved given the presence of MCC and planned accordingly. This nurse participant described goal setting and how it was used to engage patients in self-management activities:

Often their main concern is the embarrassment of incontinence. They will cut themselves off from going out or spending time with family and friends and doing anything physical because they are so nervous about the incontinence issue. And so just saying that with this change in lifestyle and some of the small changes [drinking more water], they can really get a better quality of life and spend more time with grandchildren enjoying them, and that gets it really high on their interest list. (02)

The goals were based on what the client could and wanted to do. Nurses also elicited caregiver input on feasibility and practicality of goals. For some of the participants' clients, continence was not the goal but rather a reduction in product use, incontinence episodes, or nighttime voids: "If people have many complex comorbidities then you may decide to help them manage the incontinence and not actually make any suggestions for improvement" (03).

Treating T2DM and UI together. The participants explained that they provided education to the older adult, family caregiver, and personal support worker (PSW) if involved on UI, diabetes control, and the relationship to other chronic conditions. They often described how they had to address the older adults' lack of recognition of the relationship between T2DM and UI, as this participant described: "One would have to really do quite a bit of teaching to get them to connect the dots" (02).

The participants described several other strategies, such as supporting older adults to engage in physical and social activities as a distraction from health problems related to MCC, and changes to dietary and fluid intake (i.e., improving clear fluid intake, increasing dietary fibre). Participants felt that interventions to attain optimal, personalized glycemic control would improve both T2DM and incontinence.

Addressing financial barriers. Participants indicated that many older adults faced financial barriers to adequate care of T2DM and UI: “You get a senior on like CPP [Canada Pension Plan], they can’t even afford incontinence pads, let alone better foods” (05). Due to the high cost of incontinence products, the participants witnessed many clients using homemade incontinence products that put them at risk for skin breakdown and infection. As such, nurse participants would try to intervene by connecting older adults to programs that offset the costs of incontinence products but only one municipality across the three LHINs provided this type of financial support.

Living well with diabetes was described as financially impossible for some clients served by the participants:

Are they actually able to afford and purchase the food items that we are suggesting they take? Are they actually able to get these items that are high in fiber, high in protein, low in sugar and all that? So not just nutritional things but also if I’m advocating and recommending that they get their toenails trimmed and looked after by a foot care nurse. How does that impact the oftentimes fixed income that they have because it’s not the only expenditure that I’m suggesting to them? (13)

Managing T2DM with insulin was also very costly for older adults. A few nurses educated clients on how to access provincial funding for diabetes supplies (e.g., needles

and testing strips) but were challenged in facilitating this process when working with clients who had not filed income tax returns. Where available, the nurse participants connected older adults to free, outpatient foot-care clinics. Participants provided other examples of financial barriers to clients' overall self- management, including transportation to medical appointments and purchasing home-care services or retirement-home living. However, not all nurse participants felt it was their role to address their clients' financial barriers.

Optimizing diabetes management. Nurse participants used multiple interventions to manage T2DM. They believed that many older adults may not have had or did not recall previous diabetes education: “I think with the older adult, because they probably have had it for years and years, probably years ago when they were first diagnosed, the emphasis on education on diet probably wasn’t as strong as it today” (05). Nurses also raised concern that many older adults do not monitor their blood glucose even when that information would inform their self-management: “They’ve been to the diabetic clinics before in the beginning and they’ve been shown what to do, but complacency sets in and a lot of times they just have so many other comorbidities that diabetes is kind of low on the scale” (09). Furthermore, the participants observed that some older adults did not perceive exercise as a component of self-management for T2DM.

Thus, participants provided education to clients and their caregivers on monitoring their diabetes and preventing diabetes-related complications (i.e., blood pressure, annual eye exam): “I saw a gentleman today, he’s got severe neuropathy, and he didn’t know that he should be checking his feet every day. That’s a pretty basic thing to

know” (15). The nurse participants described making referrals for older adults to outpatient or in-home (much less available) diabetes education programs: “If people are able to get out and interested in their disease, there are enough classes that they can actually go to and learn more about it” (14).

The nurse participants also connected with primary-care physicians to address suboptimal diabetes control. This was most challenging when clients were homebound related to other chronic conditions, as this nurse explicated:

How can we advocate for these things to happen because in home care there’s a lot of obstacles to getting them done? Say for example, the lab tests, how can we get them every three months, if they’re not really mobile and they’re stuck at home, how can we advocate with the help with the LHIN to have the home-care lab done so that the doctor actually has the results to be able to determine where to go from there? (13)

Nurse participants identified that some health-care providers under-treated hyperglycemia in older adults due to the belief that tighter control was not required or due to concern for risk of hypoglycemia in frail older adults with MCC.

Promoting continence. Clients who were living with UI for a long time also presented unique challenges to the nurse participants. Many older adults had not received proactive or preventative treatment for UI at the onset. Nurses indicated that older adults often felt that UI was not treatable and an unfortunate consequence of aging, a misconception reinforced by health-care professionals. These long-held beliefs were also complicated by the stigmatizing nature of UI, as elucidated by this participant:

Urinary and fecal incontinence, for some people, is a very embarrassing scenario, either that or it’s a scenario where they assume that being incontinent, whether it’s

the bladder or bowel, is part of the aging process. Have been told by their doctor, “Well, you’re getting older and it’s just part of your life and you’re just going to have to live with it,” which still happens as of today. (01).

This nurse continence advisor participant argued that home care should have greater emphasis on treating UI: “I would certainly intervene with continence more because it affects people’s quality of life and their interaction with family and friends and so that is a huge implication that they [home-care decision makers] don’t recognize. It also predisposes them to falls” (09). Interventions to manage UI described by the nurse continence advisor participants were comprehensive and included: recommending products, educating on urinary tract infection prevention in order to avoid repeated antibiotic use, assessing and treating fecal incontinence, resolving constipation, teaching pelvic floor muscle exercises, recommending adaptive equipment (e.g., commode, urinal), reduction of caffeine intake, and advocating to primary-care physicians on de-prescribing medications contributing to UI, such as sedatives. For clients with dementia, the participants described troubleshooting with PSWs and caregivers regarding challenging behaviours when changing incontinence products and toileting.

Participants identified that they would request a nurse continence advisor referral through the home-care coordinator or reach out directly to a nurse continence advisor for advice if one was employed by their agency. Some of these participants shared that they did not have knowledge of continence promotion strategies to be able to independently intervene:

So oftentimes because my role was focused on diabetes—although it does go into a little bit of foot care and incontinence as well—I find that I don’t often give out

advice [about UI]. Just because, first of all, my knowledge, I don't think, is to the point where I could be giving out advice before I consult someone else. (13)

Nurses indicated that their ability to provide holistic care for T2DM and UI was often challenging due to the current focus on short-term, post-acute care within the home-care sector. As this participant revealed:

So, it used to be that they [home care] looked after seniors primarily in the home and so people went into hospital, got discharged, and came home. And now the LHIN is being mandated to get people out of the hospitals faster. So, the hospitals are wanting to shuffle people out and I think that those pressures are huge and I think that that's why they've [home care] gone to this sort of task-orientated care. (09)

This task orientation was due to changes in “reason for referral” from home-care coordinators—such as wound care or catheter care—and the allocation of a limited number of visits. This nurse explained that she no longer had clients on long-term service for chronic disease management:

It is a big change and I don't think that was for the better. We would have the people that we had on for monitoring that we saw once a week [but now] you'd get them back on [service] because they'd been in the hospital because nobody made that phone call [to the physician] to say “Hey, Mrs. Jones's feet are getting puffy, could we increase her Lasix?” (12)

Participants noted that short visit lengths and being paid by the visit (rather than by the hour) contributed to task-focused, rather than holistic, person- and family-centred care. Many of the participants were caring for older adults with diabetes who also had ulcers. They shared feeling rushed in a 30-minute visit that included travel, documentation, care, and education: “It provides a challenge but at the same time you can't ignore the client's needs” (11). These time pressures had negative consequences,

such as keeping conversation to a minimum and focusing on the task rather than other pressing client concerns:

I think it's the system that perpetuates the "get it done fast" and the focus is on the task instead of on the person. So, let's pay this half an hour to do a dressing and you can still address diet and that kind of stuff while you are doing that dressing but people are in and out so fast that the client doesn't have time to tell them that their daughter died last week. (09).

Collaborating with the interprofessional team. Given clients' MCC, they often received care from multiple providers (e.g., primary-care physician, physiotherapist, occupational therapist) across multiple settings (e.g., home care, acute care, primary care). While nurse participants identified the value of collaborating with the interprofessional team, they indicated that they had few opportunities to do so. As well, they encountered barriers when they attempted to work together, including not having an integrated communication system.

Working with multiple care providers. When nurses worked with other interprofessional team members, they found this incredibly valuable to supporting care of this population. For example, some nurses shared that, over time, they had developed trusting relationships with primary-care physicians and these physicians valued and relied on their expertise and updates on clients. As well, one nurse continence advisor participant highlighted the value of collaborating with PSWs in promoting continence: "I really like working in collaboration with the PSWs. They're my eyes when I can't be there" (08). Some nurse participants felt that their clients benefited when they

collaborated with occupational therapists regarding home safety assessments to prevent falls and with dietitians about nutritional strategies to live well with diabetes.

However, participants felt that they had limited opportunities to collaborate with other home-care providers. They described a “disconnect” between service providers as they worked with different agencies and out of different offices (13): “Most of the time it’s through the patient’s word: ‘the OT [occupational therapist] told me this’, ‘the nurse told me that’” (10). The nurses shared that even when another home-care provider was involved, that professional’s willingness to be a team player determined the extent of the collaboration: “They [occupational therapists] don’t leave their reports in the home and a lot of the time I don’t even know who they are, I just know that they came” (11).

Also, the participants shared that there is no formal, built-in process to regularly collaborate with other providers both within and outside of home care. For example, this participant described her experiences attempting to collaborate with primary-care physicians:

Some of the physicians you call them, they call you right back, excellent discussion and things move ahead really well. Others, you call, and like I’m waiting for a physician to call me right now about somebody who actually has, I think, an infected diabetic ulcer. (14).

The participants reported that agency policies dictated that changes to a care plan be communicated to the PSW supervisor (registered nurse or registered practical nurse), who relayed the information to the PSW, not allowing for direct PSW-nurse collaboration.

Practicing without an integrated communication system. The participants noted that access to and sharing of health information within home care and with other health-

care settings was important in providing holistic, safe care and fostering team collaboration but was fragmented and uncoordinated. The participants reported that each home-care agency had its own health record for each client (paper or electronic). “The thing that would be ideal, if we had better ways to communicate with each other. You know, there’s no linkages still where we could communicate in the patient’s chart from the LHIN. So, for example, if we could ever document so that we could all read the notes” (03). Participants also had inconsistent access to the home-care electronic health record. Participants explained how the home-care coordinator routinely completed a standardized, interRAI assessment with clients but this document was not accessible to all participants through the online, LHIN-hosted platform. Some participants reported referring to the interRAI assessment in order to not duplicate assessments:

Ninety-nine percent of the time we get the RAI included with the referral and that just gives me an idea when I look at it, what I’m going to be walking into.

Sometimes I’ll pull off data from it and put it onto my assessment [form]. (12).

However, most participants revealed that they did not understand the purpose of the interRAI assessment or how to interpret the information within this document: “I mean it was page, after page, after page of ... If there was a way where they could take the yes/no answers and just spit them out on a page, but I never really saw a kind of summary of things” (14).

Participants did not have access to primary-care or acute-care electronic health records. Instead, the participants revealed that they expended time and energy daily on a cascade of work-arounds to access health information from primary care, acute care, and specialist physician providers. The participants revealed that they often had minimal

knowledge of their clients' health history and often relied on the client and caregiver accounts of what happened during a hospital admission or at specialist consultations. This participant summarized the barriers: "I think the electronic health record is the first step but it's a long way to go yet. We need visibility to the doctor's records, to the specialists, to the hospital, to the rehab facility" (12). This participant's description of trying to obtain a urologist's report elucidates the time-consuming process of obtaining relevant health information on her home-care clients:

The guy [client] said to me, "The urologist told me there's nothing I can do." Well, that doesn't help me much. So, I phoned the family doctor and he goes, "We don't have their records." "Did you change doctors?" "Well, we were back and forth and we were in an apartment for a few months, we used that doctor." I said, "Then you need to call that doctor and get his records from the urologist because the urologist won't give it to me directly." So, I'm in the process of tracking that paper to get it to the new family doctor so I can get a copy because I don't know what to do with him. (05).

Participants felt that a system-wide shared electronic health record would improve communication and coordination of care for providers across all health-care settings.

Discussion

To our knowledge, this is the first interpretive description study to explore how home-care nurses care for older adults with T2DM and UI. In summary, conducting a comprehensive nursing assessment with clients and their caregivers and providing holistic treatment for MCC was hampered by a task-focused home-care system, limited opportunities to collaborate with other health-care providers, and a lack of mechanisms to promote communication. This study's findings generated several key contributions to an understanding of how home-care nurses care for this population.

To start, this qualitative study provides insight into the approach home-care nurses took in their assessment and care of older adults with complex needs. The findings contain detailed information about the synergistic strategies used to support older adults in managing their T2DM, UI, and MCC. How nurses cared for T2DM and UI together in older adults has not previously been described in nurse-led continence intervention trials (Albers-Heitner et al., 2011; Moore et al., 2003; Williams et al., 2005; Xu et al., 2018). In the home-care context, nurses recognized that UI results from the additive effect of impairments in multiple domains (Tinetti, Inouye, Gill, & Doucette, 1995). This type of synergistic treatment of concordant conditions is recommended by researchers exploring MCC (Boyd & Fortin, 2010). The necessity to provide holistic treatment for T2DM and UI is supported by Hsu and colleagues' (2014) study of the predictors of UI in older adult home-care recipients with T2DM. Geriatric factors, such as mobility and cognitive impairment, are as important to consider as diabetic factors in the management of UI (Hsu et al., 2014).

Second, a key finding of this study was that the home-care setting does have specialist nurses who due to educational preparation and clinical experience, possess knowledge and expertise regarding continence promotion. Unlike research in other settings, where the majority of health-care providers did not know how to manage UI, participants in this study either had that expertise themselves or were aware of nurses with that expertise that they could consult with (i.e., requested a referral to a nurse continence advisor; French et al., 2016; Sui, Schindel Martin, Skelly, & Northwood, 2001). The generalist home-care nurses in this study self-identified learning needs

regarding continence promotion strategies. This finding is consistent with a qualitative evidence synthesis that found education is an enabling factor for providers in implementing behavioural interventions for UI (French et al., 2016).

Third, the focus of home care on task-focused care was a barrier to the nurses' ability to provide a holistic, person- and family-centred approach to care. This finding is consistent with recent reports on home care in Canada. Concerns with home care have been raised by the public and professionals for many years and while the government strives towards system change, the working and care conditions have not significantly improved (Baranek, Deber, & Williams, 2004; Donner et al., 2015; Home Care Ontario, 2019). A broader, system-wide reorientation from a single task or "single condition paradigm" is required to fully implement person- and family-centred care (Entwistle et al., 2018; Grembowski et al., 2014, p. S11). While the goal of health care is to deliver holistic care to meet older adults' needs, the system must have the capacity to do so and it does not as currently structured (Grembowski et al., 2014).

Fourth, the nurses identified the need for improved collaboration among home-care providers and between home-care and primary-care providers in caring for older adults with T2DM and UI. The benefits of interprofessional collaboration in the care of older adults with MCC is supported by research evidence and this absence of standard-operating procedures to facilitate collaboration is a significant care gap for this home-care population (Baxter & Markle-Reid, 2009; Boult et al., 2009). For example, a qualitative exploration of interprofessional home-care team members involved in a fall prevention intervention found that face-to-face, regularly scheduled communication through team

meetings enhanced collaboration more than their typical “asynchronous” voice mail or email communication (Baxter & Markle-Reid, 2009, p. 3).

Fifth, the finding of the need for formal mechanisms to improve communication and coordination of care across settings—home care, primary care, acute care—is noteworthy. Recent reports regarding health-care system reform and care of older adults with MCC recommend the implementation of an integrated, intersectoral electronic health record to improve communication and coordination of care (Better Home Care in Canada Partners, 2016; Blaum et al., 2018; Donner et al., 2015; Home Care Ontario, 2019). Also revealed was that, although the interRAI home-care standardized assessment has been mandated in Ontario since 2002, not all nurses had access to the interRAI assessments (Heckman, Gray, & Hirdes, 2013). Furthermore, many home-care nurses did not know how to use the outputs of these assessments as designed to identify health concerns, plan care, and monitor outcomes over time (Heckman, Gray, & Hirdes, 2013). Other research has demonstrated the feasibility and usefulness of sharing interRAI home-care assessments in improving interprofessional communication and potentially decreasing assessment duplication and workload (Guthrie et al., 2014). The absence of an integrated health record and supportive health information technology negatively influences system capacity to meet the needs of older adults with MCC (Grembowski et al., 2014).

Implications

These findings have generated implications for nursing practice, policy, and research. From a practice perspective, a comprehensive geriatric assessment and holistic treatment plan is required to promote continence and improve T2DM management for home-care clients. Further research is warranted to validate the key components of a continence-promoting intervention for this population as articulated by the nurses in this study. A systematic process for educational and consultative opportunities between generalist home-care nurses and those specialized in continence is required in home care. The findings suggest that providing continence education to home-care nurses would be helpful. Many of the components of a continence-promoting intervention are within home-care nurses' scope of practice (e.g., resolving constipation) and other components (e.g., de-prescribing, addressing financial barriers) could be learned and adopted. However, given current home-care system capacity, it will be difficult to deliver this type of complex intervention. Furthermore, until a truly integrated communication system is implemented, policies regarding LHIN contracts with service providers should be amended to change providers' status to "health information custodians" so that home-care nurses could at a minimum have access to acute-care electronic health records to better care for clients (Home Care Ontario, 2019).

These findings also have implications for research. Further study is required to inform nursing care for older adults with T2DM and UI receiving home-care services. First, this understanding would be enhanced by obtaining the experiences of home-care coordinators and primary-care providers regarding interprofessional collaboration and

their perspectives on how to improve communication and coordination of care across settings. Second, this improved understanding could lead to design and testing of strategies to enhance home-care teams' interprofessional collaboration in the care of clients with T2DM and UI or other complex conditions. Third, the findings from this study will be considered along with the results of the larger study's quantitative strand and qualitative strand on client experiences to identify the key components of a complex intervention. This newly designed intervention could also be subjected to a consensus-building process with home-care nurses, nurse continence specialists, diabetes specialists, and home-care interprofessional team members to determine team roles in managing the complexity of living with T2DM and UI.

Study Strengths and Limitations

The diversity of roles of the study participants (i.e., generalist, specialist, advance practice) and their wealth of experience in home care shows representative credibility, in that the results were informed by a variety of sources (Thorne, 2016). Analytic logic is evident in the descriptions of data collection, data analysis, and findings inclusive of participants' quotes (Thorne, 2016). Interpretive authority was ensured by MN's reflexive journaling, and the authors' participation in coding, analysis, and writing. As well, the first author's experience as a home-care nurse provided a contextual understanding of current practice. Finally, the rationale for undertaking the study—a clinical dilemma without an evidence base to inform a resolution—ensured disciplinary relevance of the study findings.

The complexity model was very useful in informing study design and analysis as it ensured that a broad range of potential factors affecting older adults' needs for services

were explored (Grembowski et al., 2014). Based on this study's findings, interprofessional collaboration should be added as an influencing factor in the health system component of the model.

This study was limited as it captured the experiences of experienced, rather than novice, home-care nurses and was conducted in only three LHINs in one province. As well, the perspectives of home-care coordinators were not captured but participants did describe their experiences with those professionals. Also, as the participants' practice was not observed, the findings are reliant on their accounts of how they practice.

Conclusion

These findings enhance understanding of how home-care nurses care for older adults with T2DM and UI. Nurse participants reported using a comprehensive, person- and family-centred approach to the care of older adults that included attending to the complex interplay of MCC with T2DM and UI and the social determinants of health. Nurses reported multiple barriers in providing comprehensive care due to the fragmented and task-focused nature of home care and other health services.

Conflict of Interest

Dr. Sherifali reports investigator-initiated funding from AstraZeneca. The other authors declared no potential conflicts of interest regarding authorship, research, and/or publication of this article.

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CHAPTER SEVEN

Mixed Methods Analysis and Interpretation

Introduction

The overall goal of this mixed-methods research (MMR) study was to better understand the complexity of living with type 2 diabetes mellitus (T2DM) and urinary incontinence (UI) for older adults receiving home-care services. As detailed in Chapter 3, the integrated mixed-methods research question was: What are the components of complexity that older adults with T2DM and UI and the nurses that care for them experience in the home-care context and how could an understanding of these components inform care approaches for this group of older adults? The term ‘components’ refers to the specific factors that influenced older adults’ needs for services and where there were gaps in services: the need-services gap (Grembowski et al., 2014). This chapter will describe the mixed methods analysis and provide a narrative synthesis of the extent to which the data converged (come together as a unified whole) or diverged (disagreed or conflicted) to answer the MMR question (Creswell & Plano Clark, 2018; O’Cathain, Murphy, & Nicholl, 2007). As well, the mixed-methods interpretation of the whole data set produces a more complete understanding of the complexity of living with T2DM and UI for older adults receiving home-care services (Bazeley, 2018). This knowledge will be used to inform the development of strategies to enhance care for this population of older adults and will be detailed in the final chapter.

Mixed-Methods Analysis

As discussed in chapter 3, the findings from the quantitative and qualitative strands were synthesized to inform a mixed-methods interpretation (Creswell & Plano Clark, 2018). The complexity model components, the findings from the quantitative study on the prevalence and correlates of UI in older adults with T2DM using home-care services, and the findings of the qualitative studies on the experiences of older adults with T2DM and UI, and the experiences of nurses caring for older adults with T2DM and UI were examined in a joint display to facilitate an understanding of how these factors influenced the need-services gap (refer to Table 1; Bazeley, 2018; Creswell & Plano Clark, 2018; Moffatt, White, Mackintosh, & Howel, 2006). Findings were categorized as either reflecting client needs (characteristics of the person; health, function and well-being; and social support) or the capacity of the system to meet those needs (health care system and community resources; Grembowski et al., 2014).

The rationale for mixing methods in this study was to achieve a more complete understanding than could be gathered from each strand separately, explain context, and provide a diversity of views (Bryman, 2006). Thus, the results were examined for convergence and divergence to better understand the nature of the problem of UI in older adults from a quantitative and a qualitative perspective and reveal the need-services gap. The quantitative strand (cross-sectional study) provided objective information on the prevalence and correlates of UI, whereas the qualitative strand (interpretive description study) provided contextual information on older adults' experiences managing T2DM and UI and how nurses cared for older adults with T2DM and UI.

Mixed Methods Synthesis

Person and Social Support Side of the Need-Services Gap

The results of the mixed methods analyses suggest that the need-services gap is influenced by personal characteristics, such as number and severity of chronic conditions, and adequacy and availability of social support (Grembowski et al., 2014). The greater the complexity, or gap, the poorer the health outcomes and the lower the quality of care (Grembowski et al., 2014).

Person. The results from all the strands found that the daily challenges of living with T2DM, UI, and geriatric syndromes in this population affected the level of need for services and made the delivery of those services more difficult. Geriatric syndromes are due to the accumulated effects of impairments in multiple domains, and if not targeted holistically, can lead to further functional decline (Tinetti, Inouye, Gill, & Doucette, 1995). Evidence from the quantitative strand demonstrated that older adults with UI were 1.23 times more likely than those without UI to make economic trade-offs (95% confidence interval [CI]: 1.12, 1.34). In the qualitative strand, older adults' experiences, and some of the nurses' experiences, also supported the importance of addressing financial barriers but not all nurse participants felt it was their role to intervene in this regard. Though nurse participants indicated that it was important to explore and consider the values and preferences of their clients and caregivers, older adult participants shared that their unique needs and preferences were not consistently considered.

The results from the qualitative strand showed that nurse participants were able to describe how they intervened to support older adults living with both T2DM and UI but

found it challenging to provide holistic and comprehensive care to this population in order to promote continence and well-being. The results of the quantitative strand indicated that a third of older adults (33.7%) with T2DM experienced daily or more frequent UI and older adults with UI were 8.04 times more likely to trigger the urinary incontinence clinical assessment protocol than older adults without UI (unadjusted odds ratio [OR] 95% CI: 7.82, 8.32). Older adults reported resignation that UI was a condition that must be endured. These findings highlighted that while UI is amenable to treatment, older adults did not receive the home-care nursing services that could improve their UI.

Older adults with T2DM and UI in the quantitative strand had on average 6.68 chronic conditions; 1.69 more chronic conditions than older adults who were continent. In the multivariable analysis, older adults with UI were 1.83 times more likely than those who were continent to have multiple chronic conditions (MCC; 95% CI: 1.74, 1.93). This finding converged with the qualitative strand as older adults expressed the daily challenges of living with MCC and how it negatively affected their self-management regimens and receiving treatment for UI. As well, the nurse participants described how they considered the presence of MCC in their assessment, goal setting, and home-care treatment plan.

The results of the quantitative strand demonstrated that older adults with T2DM and UI were more likely to have cognitive impairment, fecal incontinence, and falls than older adults without UI. In the multivariable model, older adults with UI were 2.37 times more likely than those who were continent to have some degree of cognitive impairment (95% CI: 2.28, 2.47). This diverged from participants' perspectives as no one self-

reported having cognitive impairment in the qualitative strand. However, nurse participants noted that the presence of cognitive impairment (diagnosed or undiagnosed) was a common concern in their clients and very important to consider in care planning. Older adults with T2DM and UI were 8.04 times more likely to experience fecal incontinence compared to older adults who were continent (unadjusted OR 95% CI: 7.82, 8.26). Convergent information was found in the qualitative strands with some participants reporting fecal incontinence, and nurses asking about and addressing this concern in their home-care visits. Older adults with UI were 1.22 times more likely to have fallen in the past 90 days than older adults who were continent (95% CI: 1.19, 1.26). Many participants talked about the negative impact of falls on themselves and their caregivers. Nurse participants noted that UI resulted in an increased risk of falls and included an assessment of falls in their comprehensive assessment of older adults with T2DM and UI.

Older adults with T2DM and UI were 1.24 times more likely to have made economic trade-offs than their continent peers (95% CI: 1.12, 1.38). Making economic trade-offs is defined in the Resident Assessment Instrument (RAI-HC) as not purchasing prescribed medications, sufficient home heat, necessary physician care, adequate food, or home care due to limited funds (Morris et al., 2012). This quantitative finding converged with the finding that older adult participants struggled financially to pay for costs not covered by the health-care system, such as incontinence products, insulin administration and testing supplies, and attendance at day programs. Nurse participants also reported financial barriers in their home-care clients' ability to eat balanced meals and access

services, such as foot care. However, some nurse participants noted they did not feel it was their responsibility to intervene to address financial barriers.

Social support. A convergent finding across the strands was that older adults were reliant on family caregivers and these caregivers were under tremendous burden. This burden negatively affected caregivers' ability to continue in their caregiving roles and contributed to older adults' needs for services. While nurses sought to mitigate caregiver burden, older adults felt that their caregivers were not adequately supported.

The results of the quantitative strand found that caregivers of older adults with T2DM and UI were 1.31 times more likely to experience feelings of distress, anger, or depression, compared to caregivers of older adults with T2DM who were continent (95% CI: 1.27, 1.35). A complementary finding in the qualitative strand was that older adult participants were "counting on a caregiver" for support with many activities. Both older adult participants who received caregiver support and those who were the caregiver to a family member described the burden of this responsibility. Nurse participants described being mindful of the caregiver in their assessment, goal setting, and care planning and the importance of alleviating caregiver burden. This diverged from the experiences of older adults who felt their caregiver was not adequately supported.

Health, function, and well-being. Older adults had poor functioning in both activities of daily living (ADL) and instrumental activities of daily living (IADL) and this was recognized by both older adults and nurse participants. Older adults struggled to balance treatments offered for individual chronic conditions with all their other

conditions. Nurses considered functional abilities in their assessment and care-planning. Maintaining social activity and having fun was emphasized by older adults to sustain health and well-being but was not a focus for nurses in their treatment plans.

The results of the quantitative strand demonstrated that older adults with T2DM and UI were more functionally impaired in ADLs (adjusted OR 5.31; 95% CI: 5.14, 5.50) and IADLs (unadjusted OR 4.58; 95% CI: 4.34, 4.83) than their peers who were continent. The qualitative strands converged with those findings. Older adult participants shared that difficulty with balance, impaired mobility, and other symptoms, such as shortness of breath, interfered with their function and self-management. As well, many participants described being dependent on caregivers and/or personal support workers (PSW) for both ADL and IADL functions. Nurse participants also assessed functional abilities, including caregivers' ability to continue to provide support with both ADL and IADL activities. For example, nurses recommended exercise to promote function and advocated for enhanced PSW services to address changes in clients' functional status. As well, some nurse participants noted the benefit of collaborating with an occupational therapist to enhance function and prevent falls.

The quantitative strand did not directly capture information about older adults' well-being. In the qualitative strand, however, older adults described the importance of having fun and staying social as part of their caring for their MCC. This diverged from nurses' perspectives as only a few participants mentioned the importance of social activity but more as a distraction from medical problems and none of the nurses touched on having fun and finding joy as a component of well-being for this population.

Services Side of the Need-Services Gap

The need-services gap was influenced by the capacity of the health system and community resources to meet client needs (Grembowski et al., 2014). Service capacity is influenced by home-care services, the organization of the health-care system, and access to community resources outside of the health-care system (Grembowski et al., 2014).

Health system. The findings from both research strands suggested that home-care delivery and the larger health-care system influenced the need-service gap for older adults with T2DM and UI. Nurses reported that supporting older adults with T2DM and UI was challenging given the current focus on post-acute care in home care, short visit lengths, and the lack of formal opportunities for interprofessional collaboration. As well, this population, who were at risk for adverse outcomes, received very little professional home-care services.

The results of the quantitative strand showed that older adults with UI were 2.61 times more likely to be receiving PSW support in the past week compared to older adults who were continent (unadjusted OR; 95% CI: 2.53, 2.69). This is consistent with nurse participants' observations that older adults with T2DM and UI had functional, cognitive, and social needs requiring formal support. However, older adult participants felt that the home-care services they were receiving did not always meet their individual needs. For example, they described problematic waitlists for PSW services, discontinuity of PSW service provider, and inconsistent provision of homemaking and meal preparation services. Some participants noted that PSWs did not possess the requisite knowledge to care for them completely (e.g., catheter care).

The results of the quantitative strand indicated that the older adult participants were receiving few professional services. Just over one-quarter (28.5%) of older adults with T2DM and UI were receiving home-care nursing services. Yet, the nurse participants in the qualitative strand believed that providing holistic nursing care improved the health and well-being of older adults with T2DM and UI. In contrast, many older adults described the tasks that nurses completed, such as wound care or intermittent catheterization, rather than a more comprehensive assessment and treatment of their individual needs. This was congruent with the nurse participants' description of home-care policies that affected their care including task-oriented reasons for referrals, short visit lengths, being paid by the visit, and limits on the total number of visits.

Few older adults with T2DM and UI received in-home physiotherapy (13.4%) and occupational therapy (16.9%). However, nurse participants noted that collaborating with an interprofessional team enhanced care provision for this population, such as consulting with an occupational therapist regarding home safety optimization. Furthermore, only a third (32.5%) of older adults with T2DM and UI had seen their family doctor in the past week. Older adult participants discussed difficulties getting out of their homes to see their primary-care provider.

This finding of limited professional service provision is surprising given that the population was at very high risk for institutionalization (unadjusted OR 7.42; 95% CI: 7.16, 7.68) and hospitalization (unadjusted OR 1.37; 95% CI: 1.31, 1.43) compared to older adults without UI. Older adults with T2DM and UI were also more medically unstable (higher Changes in Health End-Stage Disease and Signs and Symptom [CHESS]

score) and had greater care needs (higher Method for Assessing Priority Levels [MAPLe] score) than older adults who were continent. Many of the older adult participants described serious health crises, such as hospitalization for urinary tract infection with delirium. Thus, the quantitative and qualitative strands described a complex population at risk for adverse health outcomes, with high care needs, that were receiving remarkably little professional services to mitigate risks for institutionalization or hospitalization.

A complementary finding not captured in the quantitative strand but regarded as important by the nurse participants were the challenges of practicing without an integrated communication system. Working without an electronic health record threatened nurses' provision of safe care due to minimal knowledge of clients' health history. The absence of an electronic health record also impeded interprofessional collaboration. In addition, existing systems, such as the sharing of standardized, comprehensive RAI-HC assessments, were not being used for maximum benefit in understanding clients' needs and care planning.

Community resources. Community resources have the potential to positively support older adults to live well with T2DM and UI but the lack of community navigation was identified as a gap. The results of the quantitative strand found that few older adults with UI (3.9%) used adult day programs in the past week. In the qualitative strand, older adults discussed the importance of adult day programs but divergently, the nurse participants did not mention this as a treatment option. Older adults additionally noted that they had found community programs themselves without any health-care professional system navigation.

Mixed-Methods Interpretation

The understanding revealed by the whole data set provides evidence of the key influencing factors on the need-services gap for older adults with T2DM and UI receiving home care (Grembowski et al., 2014). The complementary and divergent results from the quantitative and qualitative strands in this study highlight the importance of considering empirical evidence and clients' and nurses' perspectives and about the nature of the problem to inform intervention design (Sidani & Braden, 2011).

Key factors from the *person, social support, and health, function, and well-being side* included: (a) challenges of living with MCC, geriatric syndromes, medical instability, and high care needs; (b) financial barriers; (c) lack of understanding of older adults' values and preferences by health-care providers; (d) significant caregiver burden; (e) functional impairments; and (f) importance of social activity. Factors influencing the *services side* of the need-services gap were: (a) minimal provision of nursing and interprofessional home-care services; (b) the task-focused structure of home care; (c) minimal interprofessional collaboration; (d) lack of an integrated communication system; and (e) underutilization of and lack of navigation to community resources.

Conclusion

The findings from the mixed method study revealed that the interplay of T2DM and UI in older adults creates complex, unmet needs that the present delivery of home care is not able to consistently meet. This improved understanding of the components of complexity of living with T2DM and UI for older adults receiving home care can inform

the generation of implications for provision of home-care services to this population, as discussed in the final chapter.

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Table 1

Joint Display of Quantitative and Qualitative Data and Mixed Methods Interpretation of Results

	FACTORS INFLUENCING NEED-SERVICES GAP		NEED-SERVICES GAP		
	Quantitative		Qualitative	Mixed Methods Interpretation	
Complexity Model Components	Prevalence and Correlates of UI	Older Adults	Nurses	Convergent	Divergent
NEED					
Person (chronic conditions, characteristics [age, sex, race, ethnicity, income], values and preferences)	Prevalence: <ul style="list-style-type: none"> 33.7% of older adults with T2DM had at least daily or more frequent UI Correlates: <ul style="list-style-type: none"> 82.17 mean age (2.2 years older compared to older adults who were continent) 63.6% female (compared to 54.5% females who were continent); OR^b 1.87 (95% CI: 1.82, 1.83) 6.68 average number of chronic conditions (1.69 more conditions compared to older adults who were continent); MCC ≥ 2 OR^b 1.83 (95% CI: 1.74, 1.93) 1.7% made trade-offs due to limited funds 	<ul style="list-style-type: none"> Enduring urinary incontinence: “patch it in pads” Struggling to manage diabetes, incontinence, and multiple chronic conditions: “a balancing act” Covering the costs of care: “I can’t afford it” 	<ul style="list-style-type: none"> Conducting a comprehensive nursing assessment with client and caregiver Providing holistic treatment for MCC <ul style="list-style-type: none"> -Determining goals -Treating T2DM and UI together -Addressing financial barriers -Optimizing diabetes management -Promoting continence 	<ul style="list-style-type: none"> Living with MCC and UI affected level of needs for services and made service delivery very challenging. 	<ul style="list-style-type: none"> Financial barriers and individual preferences were important influencers of the need for services but were inconsistently considered by providers.

	FACTORS INFLUENCING NEED-SERVICES GAP			NEED-SERVICES GAP	
	Quantitative		Qualitative	Mixed Methods	Interpretation
Complexity Model Components	Prevalence and Correlates of UI	Older Adults	Nurses	Convergent	Divergent
	<p>(compared to 1.6% of older adults who were continent); OR^b 1.23 (95% CI: 1.12, 1.34)</p> <ul style="list-style-type: none"> 90% had some degree of cognitive impairment (compared to 71.0% of older adults who were continent); OR^b 2.37 (95% CI: 2.28, 2.47) 50.1% had ≥ 1 fall in the last 90 days (compared to 42.3% of older adults who were continent); OR^b 1.22 (95% CI: 1.19, 1.26) 61.1% had fecal incontinence (compared to 16.4% of older adults who were continent); OR^a 8.04 (95% CI: 7.82, 8.26) 				
Social Support (family, other sources)	<ul style="list-style-type: none"> 40.6% of caregivers experienced distress compared to 26.2% 	<ul style="list-style-type: none"> Counting on a caregiver: “he does everything” 	<ul style="list-style-type: none"> Conducting a comprehensive nursing 	<ul style="list-style-type: none"> Older adults were reliant on caregivers and 	<ul style="list-style-type: none"> Nurses sought to mitigate caregiver

	FACTORS INFLUENCING NEED-SERVICES GAP			NEED-SERVICES GAP	
	Quantitative		Qualitative	Mixed Methods	Interpretation
Complexity Model Components	Prevalence and Correlates of UI	Older Adults	Nurses	Convergent	Divergent
	<ul style="list-style-type: none"> of caregivers of older adults who were continent; OR^b 1.31(95% CI: 1.27, 1.35) 53.5% of primary caregivers lived with the older adult (compared to 54.0% of older adults who were continent) 		<ul style="list-style-type: none"> assessment with client and caregiver Providing holistic treatment for MCC 	<ul style="list-style-type: none"> these caregivers experienced burden that negatively affected their ability to continue in caregiving role and influenced older adults' needs for services. 	<ul style="list-style-type: none"> burden, yet older adults felt their caregivers were not adequately supported.
Health (function, well-being)	<ul style="list-style-type: none"> 53.6% had moderate/severe ADL impairment (compared to 14.5% of older adults who were continent); OR^b 5.31 (95% CI: 5.14, 5.50) 95.9% had IADL difficulty in ≥ 1 area (compared to 83.8% of older adults who were continent); OR^a 4.58 (95% CI: 4.34, 4.83) 	<ul style="list-style-type: none"> Struggling to manage diabetes, incontinence, and multiple chronic conditions: “a balancing act” 	<ul style="list-style-type: none"> Conducting a comprehensive nursing assessment with client and caregiver Providing holistic treatment for MCC 	<ul style="list-style-type: none"> Older adults struggled to balance treatments offered for individual chronic conditions with MCC and nurses assessed/treated functional abilities. 	<ul style="list-style-type: none"> Older adults emphasized the importance of maintaining social activity but this was not a focus for nurses.
SERVICES Health Care System (home care; organization)	<ul style="list-style-type: none"> 76.2% received PSW in the last week (compared to 55.2% 	<ul style="list-style-type: none"> Home-care services not meeting my 	<ul style="list-style-type: none"> Collaborating with the 	<ul style="list-style-type: none"> Home-care delivery and the larger health-care 	<ul style="list-style-type: none"> Older adults were at risk for adverse

FACTORS INFLUENCING NEED-SERVICES GAP				NEED-SERVICES GAP	
Complexity Model Components	Quantitative	Older Adults	Qualitative	Mixed Methods Interpretation	
	Prevalence and Correlates of UI		Nurses	Convergent	Divergent
of health-care system; availability of electronic health record; education of providers to treat MCC)	<p>of older adults who were continent); OR^a 2.61 (95% CI: 2.53, 2.69)</p> <ul style="list-style-type: none"> • 28.5% received nurse service in the last week (compared to 29.9% of older adults who were continent) • 13.4% received PT in the last week (compared to 13.6% of older adults who were continent) • 16.9% received OT in the last week (compared to 17.5% of older adults who were continent) • 89.8% triggered institutional CAP (compared to 54.3% of older adults who were continent); OR^a 7.42 (95% CI: 7.16, 7.68) • 84.9% triggered UI CAP (compared to 41.1% of older adults who were continent); OR^a 8.04 (95% CI: 7.82, 8.32) 	needs: “it’s not individual”	interprofessional team	system was contributing to a needs-service gap for older adults with T2DM, UI, and MCC by not providing professional and supportive services that older adults required.	outcomes but received very little professional home-care services.

	FACTORS INFLUENCING NEED-SERVICES GAP		NEED-SERVICES GAP	
	Quantitative	Qualitative	Mixed Methods	Interpretation
Complexity Model Components	Prevalence and Correlates of UI	Older Adults Nurses	Convergent	Divergent
	<ul style="list-style-type: none"> 72.7% were hospitalized in the past 180 days (compared to 66.1% of older adults who were continent); OR^a 1.37 (95% CI: 1.31, 1.43) 32.5% visited a physician in the last 7 days (compared to 33.0% of older adults who were continent) 22.9% visited ER in the last 90 days (compared to 23.9% of older adults who were continent); OR^a 0.95 (95% CI: 0.92, 0.98) 34.2% had CHES ≥ 3 (compared to 24.3% of older adults who were continent); OR^a 1.62 (95% CI: 1.57, 1.66) 68.7% had MAPLe ≥ 4 (compared to 46.8% of older adults who were continent); OR^a 2.49 (95% CI 2.42, 2.55) 			

	FACTORS INFLUENCING NEED-SERVICES GAP				NEED-SERVICES GAP	
	Quantitative		Qualitative		Mixed Methods	Interpretation
Complexity Model Components	Prevalence and Correlates of UI	Older Adults	Nurses		Convergent	Divergent
Community Resources (partnerships beyond health-care system, access)	<ul style="list-style-type: none"> 3.9% attended day program in the past week (compared to 3.0% of older adults who were continent); OR^a 1.42 (95% CI: 1.32, 1.52) 	<ul style="list-style-type: none"> Descriptions of maintenance of social life involving community programs in theme: Struggling to manage diabetes, incontinence, and multiple chronic conditions: “a balancing act” 	<ul style="list-style-type: none"> No data 		<ul style="list-style-type: none"> Community resources have potential to positively support older adults to live well with T2DM, UI, and MCC. 	<ul style="list-style-type: none"> Navigation to community resources is a missed opportunity to provide care and improve health outcomes for older adults.

Note. CI = confidence interval. OR = odds ratio; T2DM = type 2 diabetes mellitus; UI = urinary incontinence; MCC = multiple chronic conditions; Institutional CAP = Institutional Risk Clinical Assessment Protocol flags risk of entering a long-term care home in the coming months; ADL = activities of daily living; IADL = instrumental activities of daily living; CHES = Changes in Health End-Stage Disease and Signs and Symptoms; MAPLE = Method for Assessing Priority Levels; OT = occupational therapist; PT = physiotherapist; PSW = personal support worker; ER = emergency room.

^aUnadjusted odds ratios.

^bAdjusted odds ratios.

CHAPTER EIGHT

Discussion

Introduction

This final chapter will summarize the main findings from the quantitative and qualitative strands, and the mixed methods interpretation in relation to the literature. Implications will be discussed for (a) nursing and interprofessional practice; (b) education; (c) policy and health-care service delivery; and (d) future research. Finally, the strengths and limitations of the study and the complexity conceptual framework (Grembowski et al., 2014) used in the study will be presented.

Summary of Main Findings

The goal of this mixed methods research study was to better understand the complexity of living with type 2 diabetes mellitus (T2DM) and urinary incontinence (UI) for older adults receiving home-care services. The findings have contributed to an improved understanding of the experiences, needs, and health of this population of older adults, as well as strategies and barriers to providing nursing home-care services to older adults with T2DM and UI.

The findings from the analysis of the Resident Assessment Instrument for Home Care (RAI-HC) data in the quantitative strand (Chapter 4) showed that 33.7% of older adults with diabetes receiving home care reported daily or multiple daily episodes of UI. This rate is lower than the prevalence rates of 44% to 48% cited in other cross-sectional research. One explanation for this difference in prevalence rates may be due to the fact that these studies broadly defined UI as any loss of urine (e.g., less than weekly to

multiple times daily), whereas UI in this current study was defined as daily or multiple daily episodes of UI (Hsu et al., 2014; Vetrano et al., 2016). Thus, this study provides new information regarding the prevalence of severe UI in this population.

ADL impairment, cognitive impairment, female sex, the presence of ≥ 2 chronic conditions, caregiver distress, economic trade-offs, and falls were significantly associated with UI in older adults with T2DM. These findings are consistent with Hsu et al. (2014) in a cross-sectional study of mostly Asian older home-care clients with T2DM, which showed that ADL impairments (dependence on another for transferring and walking) and cognitive impairment are factors associated with UI. The current findings that female sex and falls are associated with UI in older adults are also consistent with other literature (Du Moulin et al., 2008; Chiarelli, Mackenzie, & Osmotherly, 2009). A unique contribution of this study is the finding that multiple chronic conditions (MCC), caregiver distress, and economic trade-offs are associated with UI in this population. The significance of these findings is that the management plan for UI must consider a broad range of factors when caring for a population of older adults with T2DM receiving home-care services.

Findings from the qualitative strand examining the experiences of older home-care recipients (Chapter 5) revealed the following challenging and complex experiences of living with T2DM and UI: (a) enduring urinary incontinence: “patch it in pads”; (b) struggling to manage diabetes, incontinence, and MCC: “a balancing act”; (c) covering the costs of care: “I can’t afford it”; (d) counting on a caregiver: “he does everything”; and (e) home-care services are not meeting my needs: “it’s not individual.” This study

has provided important evidence from the client perspective on what it is like to live with T2DM, UI, *and* other chronic conditions, and how home-care services can better support this client population. Consistent with qualitative literature exploring the experiences of older adults living with T2DM, self-management support from caregivers was regarded as very helpful (Brewer-Lowry et al., 2010; Joo & Lee, 2016; Song et al., 2009; Washington & Wang-Letzkus, 2009). This dependence on caregivers for older adults with MCC and the resultant caregiver burden is in keeping with other research literature (Eckerblad et al., 2015; Gill et al., 2014; Ploeg et al., 2015).

Older participants with T2DM in other qualitative research also experienced financial burdens related to transportation, medication, etc., which is further evidence of financial vulnerability of this population of older adults (Joo & Lee, 2016; Wilson, 2012). The theme of “enduring UI” is supported in other qualitative descriptive research regarding older adults’ experiences of living with UI as these participants similarly regarded UI as an unfortunate consequence of aging (Andersson et al., 2008; Horrocks et al., 2004; Park et al., 2017).

An important finding in the qualitative strand of this mixed methods research is that older adults struggle to manage UI and all of their chronic conditions successfully and that home-care services were not consistently addressing that struggle. This finding is consistent with literature in that living with MCC has been described as challenging by older adult participants in other qualitative studies but the novel contribution of this study is that it examined the experience of UI with MCC and in the home-care context specifically (Eckerblad et al., 2015; Ploeg et al., 2017).

Another unique contribution of the study was its focus on understanding experiences of home-care nurses caring for older adults with T2DM and UI (Chapter 6). Nurses cared for this population by: (a) conducting a comprehensive nursing assessment with client and caregiver; (b) providing holistic treatment for MCC; and (c) collaborating with the interprofessional team. This care was not easy to accomplish, and required numerous, daily work-arounds of standard, home-care procedures. Some of the barriers that required work-arounds have also been reported in other qualitative research with home-care nurses: limited interprofessional collaboration (Fox, Munro, & Brien, 2006; Gifford, Graham, & Davies, 2013; Kolltveit, et al., 2017); inadequate access to specialist nurses for support (Fox et al., 2006; Gifford et al., 2013); and lack of in-home connectivity to an electronic health record (Kolltveit et al., 2017; Ploeg et al., 2017).

The approach to building a relationship over time with clients with UI and their caregivers, described in the grounded theory study by Jansen and colleagues (2013), had similar elements to how nurses in the current study described caring for their clients and caregivers. Yet, nurses in the current study provided continence promoting knowledge (e.g., prompted voiding, fluid and dietary advice, pelvic floor muscle exercises) and this was not described by the nurses in the Jansen et al. (2013) study.

The comprehensive approach to providing holistic treatment for MCC, inclusive of caregivers, described by the nurse participants in this current study has provided a novel and much-needed evidence base to inform home-care delivery for this population. The details of their assessment process, the nature of goal-setting, and care strategies—treating T2DM and UI together, addressing financial barriers, optimizing diabetes

management, promoting continence, and practicing without an integrated communication system—have produced very practical, translatable knowledge relevant to the current home-care setting.

The results of the mixed methods analysis (Chapter 7) provided a deeper understanding of the need-services gap for older adults with T2DM and UI receiving home care (see Table 1; Grembowski et al., 2014). Influential factors from the *person, social support, and health, function, and well-being side* of the need-services gap included: (a) challenges of living with MCC, geriatric syndromes, medical instability, and high care needs; (b) financial barriers; (c) lack of understanding of older adults' values and preferences by health-care providers; (d) significant caregiver burden; (e) functional impairments; and (f) importance of social activity. Factors influencing the *services side* were: (a) minimal provision of nursing and interprofessional home-care services; (b) the task-focused structure of home care; (c) minimal interprofessional collaboration; (d) lack of an integrated communication system; and (e) underutilization of and lack of navigation to community resources. This contextualized understanding informed by the necessary foundational components for intervention design—current literature, and empirical, experiential, and conceptual knowledge—has generated implications for practice, education, policy, and research (Sidani & Braden, 2011).

Implications

This mixed methods research study has generated many implications for: (a) nursing and interprofessional practice; (b) education; (c) policy and health-care service delivery; and (d) future research. The successful implementation of these implications

requires the reorientation of home care and the wider health-care system to align with the principles of person- and family-centred care and the social determinants of health in the context of integrated care delivery. As well, effective utilization of nurses in this new model of care delivery is required.

Implications for Nursing and Interprofessional Practice

There are several implications resulting from this study that should be considered for nursing practice and interprofessional team practice related to older adults with T2DM and UI in the home-care environment. See Table 1 for a summary of the intervention components to address the need-services gap experienced by older adults with T2DM and UI. In Table 1, the intervention components are mapped on to the components of the complexity model and the mixed methods interpretation. The findings suggest that integrated care delivery that involves both a person- and family-centred care and a social determinants of health approach is needed to mitigate the need-services gap for older adults with T2DM and UI.

First, the finding that nurses conducted a comprehensive assessment to determine all of the multiple contributing factors to UI in this population suggests that integrated care delivery for a home-care population of older adults with T2DM and UI should begin with a comprehensive geriatric assessment. This assessment may facilitate the early detection of UI and subsequent management of UI so it is not untreated or under-treated, as was the case for many older adult participants in this study. Based on the correlates of UI identified in this study, special attention should be given to assessment of activities of daily living, cognitive impairment, female sex, MCC, presence of a distressed caregiver,

making economic trade-offs, and falls. As well, the assessment should include the other factors that the nurse participants in the qualitative strand identified (e.g., medications, mental health, condition of home, distance to bathroom, etc).

In the Ontario home-care system, there is an opportunity to leverage the current mandated use of the interRAI Home Care (interRAI HC) as part of the assessment process (prior to 2018 the Resident Assessment Instrument for Home Care [RAI-HC] was utilized). The interRAI HC is a person-centred system that informs and guides comprehensive care and service planning, focuses on the older adult's functioning and quality of life, and assesses needs, strengths, and preferences (Morris et al., 2012). The outputs of the tool, the clinical assessment protocols and scales, should be shared with clients and caregivers in a person- and family-centred approach to care planning.

Furthermore, the interRAI HC also considers the social determinants of health. The social determinants of health can be understood as the social, economic, and political mechanisms that create differing socioeconomic positions where populations are hierarchically grouped according to gender, ethnicity/race, education, occupation and income (Solar & Irwin, 2010). Socioeconomic positions consequently influence economic circumstances, behaviours, biological factors, and psychosocial factors (Solar & Irwin, 2010). For example, there are clinical assessment protocols to address non-clinical issues regarding the home environment, informal support, and social relationships (Morris et al., 2012). Given the emphasis on addressing financial barriers shared by both older adult and nurse participants in this study, assessing social determinants of health

and intervening to mitigate health care disparities should be a component of home care for older adults with T2DM and UI.

Utilizing the interRAI HC as part of a person- and family-centred approach may help mitigate the experiences of older adults in this study that the home-care services offered were not individualized. A person- and family-centred approach to care is defined as holistic, engaging both client and caregiver as partners, empowering clients and caregivers to direct their care, and fostering independence (Canadian Home Care Association [CHCA], 2013). In this care approach, beginning with the assessment, what matters to clients and caregivers is prioritized and respected by health-care providers (Entwistle et al., 2018). Person- and family-centred care represents a movement from the traditional, provider-centred care to health-care delivery where clients and their caregivers are active partners in decision-making and planning regarding their health (Giosa, Holyoke, & Stolee, 2019). Evidence from a systematic review of home-care interventions for frail older persons noted that utilizing the interRAI HC as part of the care-planning process reduced hospital admissions and length of stay (Mello et al., 2015). However, a cluster randomized controlled trial in Germany introducing the RAI-HC did not find improved outcomes for home-care clients (Stolle et al., 2012). In a subsequent factor analysis, the researchers determined that the clients of home-care agencies who worked intensively with the RAI-HC were hospitalized less often and had better functional and cognitive performance than clients of agencies who did not work intensively with the tool (Stolle et al., 2015). The authors concluded that in order for home-care nurses to realize improvements in client outcomes, adequate implementation

of the use of the RAI-HC tool must occur with the tool introduction (including education on the use of the clinical assessment protocols in care planning) and at regular intervals (Stolle et al., 2015).

As revealed in the qualitative strand of this study, not all home-care nurses understood the outputs of the interRAI and how they could be used to inform their care and others did not even have access to the results of this standardized assessment. As well, 84.9% of older adults with UI in the quantitative strand triggered the urinary incontinence clinical assessment protocol, which should prompt care planning to improve bladder function or prevent worsening. Yet, the older adult participants in the qualitative strand for the most part did not receive care for their UI. These findings suggest that service providers may not have been provided the requisite education when the RAI-HC was mandated for use in Ontario in 2002 or ongoing continuing education (Hirdes, 2006). This is consistent with other research evidence that identified that home-care providers required education about the interRAI and its applications in order to be able to utilize the outputs in clinical practice (Guthrie et al., 2014). Also, an evaluation of the reimplementation of an interRAI assessment in an Ontario complex continuing care hospital found that staff were unaware of interRAI scales and clinical assessment protocols or how to use these outputs in care planning (Turcotte, 2018).

Second, the key finding that UI is caused by multiple interacting factors provides support for a multifaceted approach as opposed to single strategies, such as treatment of UI with a medication. This approach could be characterized as a complex intervention. A complex intervention is defined as “multiple components and their respective actions,

targeting different aspects or determinants of the same problem or different interrelated problems” (Sidani & Braden, 2011, p. 20). The findings suggest that a complex intervention for older adults with T2DM and UI would include the following components: (a) educate client and caregiver on the relationship between diabetes and UI or contributing factors to UI; (b) support glycemic control; (c) recommend fluid and dietary intake changes (e.g., reduce caffeine intake); (d) monitor and prevent complications in diabetes (e.g., education on foot care); (e) treat and manage UI (recommend products, educate on urinary tract infection prevention in order to avoid repeated antibiotic use, resolve constipation, teach pelvic floor muscle exercises, teach prompted voiding); (f) recommend adaptive equipment (e.g., commode, urinal); (g) advocate to primary-care physicians to de-prescribe medications contributing to UI (e.g., sedatives); (h) educate and collaborate with PSWs regarding promoting continence (e.g., troubleshooting with PSWs and caregivers regarding challenging behaviours when changing incontinence products and toileting); (i) address financial barriers; (j) support management of other chronic conditions; (k) treat and manage other risk factors for UI and geriatric syndromes (e.g., falls, fecal incontinence, cognitive impairment); (l) support caregivers; (m) consider treatment burden with other chronic conditions; (n) optimize or support ADL and IADL activities; (o) promote social and physical activity; and (p) provide balance and mobility training (see Table 1).

Third, the findings that older adults experienced living with MCC as challenging to balance, received care in many different settings (including community support services) by a number different providers (within and outside home care), and required a

complex intervention to manage UI, suggest that care coordination would be essential to ensure that all the components of the intervention are enacted in an integrated, not fragmented, manner. Integrated care links health and social care to enhance service coordination and improve client and caregiver experience (Kirst et al., 2017). Integrated care fosters collaboration, trusting relationships, and communication across multiple health-care providers across all settings in the health-care system and community support services (CHCA, 2013; Farmanova et al., 2019).

Enhancing the care coordinator role in home care could facilitate integrated care and ensure that the goals and needs for services of older adults with T2DM and UI are met. Research has demonstrated the value of care coordination in achieving integrated care. A review of models of care for older adults with MCC found that care-management models were associated with improved quality of care, quality of life, survival, and satisfaction with care (Boult et al., 2009). A program evaluation in an Ontario Local Health Integration Network (LHIN) found that the implementation of intense care coordination involving regular communication with primary care, reduced those waiting for long-term care placement by 25% (Daub, Goldhar, & Purbhoo, 2016). A study of older adult home-care recipients in Europe found that care coordination was effective in facilitating preventative strategies (blood pressure measurement, influenza vaccination, and medication review), and lowering caregiver distress (Onder, Liperoti, Bernabei, & Landi, 2008).

As reported in this study, older adults did not consistently receive the type of services they required to remain in their homes (e.g., meal preparation, social activity,

homemaking). Older adults with MCC receiving home-care services have needs that must be met with both clinical and so called “non-clinical” services (Boyd & Fortin, 2010). Needs related to housing, transportation, socialization, homemaking, and finances are typically not addressed within the health-care environment but rather by other sectors, such as community support services or social services (Farmanova, Baker, & Cohen, 2019). The care coordinator should be enabled and empowered to help clients identify and access community services and directly coordinate that care as opposed to the current practice of only (and not consistently) providing information to clients about the availability of these services (Williams et al., 2009). This type of system-navigation component of care coordination has been found in a scoping review of models of care linking older adults to community support services to reduce caregiver strain or depressive symptoms and increase client contact with primary care (Valaitis et al., 2017). For example, the care coordinator should arrange homemaking services for clients to assist with meal preparation or refer to an exercise and socialization community program and follow-up with those providers and the client on how these services were meeting client needs, rather than relying on the client or caregiver to be their own care coordinator. As well, the care coordinator could connect clients to beneficial social and exercise programs and monitor the impact on well-being, mobility, and UI.

Another important consideration in strengthening the home-care coordinator role for older adults with T2DM and UI is the need for coordination to occur across all settings of the health-care system. The older adults in this study received care from multiple physician specialists and this care was not consistently coordinated. It is

understood that older adults with MCC are vulnerable to very poor care at transitions from hospital to home but transitions between out-patient providers are important to consider as well (Boyd & Fortin, 2009). For example, more intensive care coordination for the participants in this study may have meant better understanding of the outcomes of specialist consultations by the clients and home-care team, improved communication amongst all care providers, and the resultant development of strategies to continue to address UI if the specialist consultation did not meet client needs.

Presently in Ontario, the home-care coordinator is the designated case manager who completes the interRAI HC assessment and coordinates the service plan. Policy changes are currently underway in Ontario with the Ministry of Health and Long-Term Care (MOHLTC) moving towards consolidating agencies, such as the LHIN, into a single, accountable Ontario Health agency (Ontario MOHLTC, 2019a). Part of this process is the development of Ontario Health Teams that will provide services to a population and include primary care, hospitals, home care, community support services, palliative care, residential long-term care, health promotion and disease prevention services, and mental health and addictions services (Ontario MOHLTC, 2019b). Given that the LHINs employ these care coordinators, the activity of care coordination could shift to direct care providers, such as the home-care nurse, community support services provider, or primary-care provider (Ontario MOHLTC, 2019a). This time of change and system re-design presents an opportunity to reimagine the care coordinator role in a manner supportive of older adults with T2DM and UI and other combinations of MCC that generate clinical complexity.

Fourth, the findings described the importance of interprofessional collaboration in caring for older adults with T2DM and UI and signal a need to improve opportunities for collaboration as well as enhance the levels of interprofessional service provision. As found in this study, many of the components of a complex intervention to manage UI in older adults with T2DM requires collaboration with other disciplines, such as working with occupational therapists, physical therapists, and personal support workers regarding activities of daily living optimization for clients. Based on the results from this study, that team must include the older adult, caregiver, and providers from home care (nurses, personal support workers, occupational therapists, physiotherapists, etc), primary care, and community services.

Interprofessional collaboration is regarded in the literature as essential to integrated care. For example, in an international cross-case synthesis of seven integrated care programs for older adults with complex needs, researchers noted that successful integration was achieved when providers collaborated and communicated with each other in the care of the same client (Wodchis, Dixon, Anderson, & Goodwin, 2015). A scoping review of integrated care with a population health approach, also noted that interprofessional collaboration was a common component in the 15 integrated care programs that they reviewed (Farmanova et al., 2019).

Thus, interprofessional collaboration must be enhanced in home-care provision to ensure that all providers are working towards the goals identified by the client and caregiver. One option to improve interprofessional collaboration is to optimize the role of the home-care care coordinator in not only brokering interprofessional services but

supporting the interprofessional team in identifying their roles and responsibilities in caring for older adults with MCC; however, this will require an investment in provider time and education. Examinations of integrated care programs in a recent cross-case analysis (Wodchis et al., 2015) and a realist review (Kirst et al., 2017), noted that time was required to build trusting relationships among the interprofessional team as they work towards becoming more integrated and collaborative. Integrated care programs were not successful when the interprofessional providers did not understand the purpose of working collaboratively, were not excited about changing their practice, and primary-care physicians were not engaged in the process (Kirst et al., 2017). However, evidence from a feasibility study of an interprofessional education intervention in home care found that this education was effective in improving communication, coordination of care, decision-making, and conflict management at six months after initial education (Bookey-Bassett, 2019).

Yet, to work effectively as an integrated, interprofessional team, processes for communication are required. As found in this study, nurses did not have a formal communication process for collaboration. They also did not have a shared electronic health record with acute care, primary care, and community and other home care agencies. An integrated information and communication technology system has been found to facilitate team communication and sharing of client health information (Kirst et al., 2017). In an analysis of Ontario's ability to use information technology to support persons with complex care needs, the authors noted that existing information technology systems did not ensure interoperability between systems connecting providers and clients

across care systems and recommended this improvement (Steele Gray et al., 2016).

However, in the integrated care programs reviewed by the afore-mentioned realist review and cross-care analysis, not all programs had successfully linked their electronic health records (Kirst et al., 2017; Wodchis et al., 2015). What these successful integrated care programs had accomplished was implementing a protocol for regular team meetings and care planning (Kirst et al., 2017; Wodchis et al., 2015). Thus, in the absence of a truly integrated communication system between health- and community-care providers and their clients and caregivers, at minimum, clear and detailed protocols for communication and formal opportunities to connect (virtually or in-person) should be formally established in interprofessional teams.

Implications for Education

These study findings support the need for continuing education of health-care providers regarding the use of a person- and family-centred and social determinants of health approach to integrated care. As well, education is required on comprehensive, geriatric assessment and the use of interRAI HC. Generalist home-care nurses require education regarding continence promotion and caring for older adults with MCC. Given these knowledge gaps and learning needs in practicing nurses and health-care providers, pre-graduate education on these topics is also necessary for learners.

Changing practice to embrace a patient- and family-centred and integrated approach to care requires support and education (Entwistle et al., 2018; Kirst et al., 2017). In a qualitative exploration of providers' (nurses, physicians, and physiotherapists) enactment of person-centred support for older adults with Parkinson's disease or diabetes,

these providers experienced tensions and uncertainties in being respectful of persons' autonomy while trying to support them to make realistic changes in their lives (Entwistle et al., 2018). Providers felt they needed educational support to learn and deal with these uncertainties (Entwistle et al., 2018).

Likewise, investment in on-going, continuing education on the principles of an integrated care model, and how to work together effectively, strengthened the implementation of integrated care in the reviewed programs (Kirst et al., 2017). A pilot study of an interprofessional education intervention to support collaborative practice in home care used a combination of education (lecture, small group discussion, case studies), reflective practice exercises, and provision of tools to facilitate collaboration (e.g., team charter document) to prepare home-care providers to collaboratively care for older adults who had experienced a stroke and their family caregivers (Bookey-Bassett, 2019). Thus, home-care providers require learning opportunities regarding team member roles, group process skills, conflict management, and decision-making to improve their collaboration (Bookey-Bassett, Markle-Reid, McKey, Akhtar-Danesh, 2016). Education on interprofessional collaboration should also be provided at the pre-graduate level for health and community support service providers to better enable them to work collaboratively upon entering the work force.

A standardized and comprehensive geriatric assessment is an important first step in enacting a person- and family-centred approach to care, yet not all of the nurse participants in this study understood the purpose and the function of the interRAI HC and the older adult participants did not always feel the plan of care was informed by their

needs. This translates to an assessment burden for older adults and their caregivers as home-care providers collect the same information multiple times and a missed opportunity to use the interRAI HC as intended to inform and guide comprehensive service planning and care. All home-care service providers should receive education on the interRAI HC outputs—the clinical assessment protocols and scales—in order to easily identify clients at risk of poor outcomes, have a common language for interprofessional care planning and collaboration, and monitor their clients' progress over time (Heckman, Gray, & Hirdes, 2013). Additionally, home-care service providers and care coordinators would benefit from education on how to utilize the interRAI HC outputs to co-create care plans with clients, caregivers, and the interprofessional team (Daub et al., 2016; Guthrie et al., 2014). Education on the interRAI suite of assessments should be part of pre-graduate health and community support service providers' education given that it is mandated for use in many settings in Ontario, including home care and long-term care (Boscart et al., 2018).

The description of the components of a complex, continence-promoting home-care intervention for older adults with T2DM and UI generated by this study would be an important educational topic for generalist nurses. This is an important point as many of the nurse participants were drawing on their expertise as nurse continence advisors (40% of participants) and number of years of practice experience (60% had ≥ 20 years of experience), compared to more novice or generalist home-care nurses. Many of the components of such an intervention described by the experienced nurses in the qualitative strand of this study are within home-care nurses' current practice expertise, such as

suggesting reduction in caffeine or educating on prevention of foot complications in T2DM. Other components—such as advocating to primary care physicians regarding de-prescribing of medications negatively affecting continence, selecting optimal incontinence product, or considering treatment burden for older adults with MCC—would likely have to be learned by generalist and novice home-care nurses.

Given the financial burden of living with T2DM and UI demonstrated in both the quantitative and qualitative strands, home-care nurses likely need education on addressing this social determinant and intervening. This education would also have to address the finding that not all nurses felt that addressing financial burden was part of their role. The provision of education on how to address low income with practical strategies may improve home-care nurses' comfort with intervening. For example, home-care nurses' knowledge could be enhanced in order to: (a) connect clients to the provincial government's Assistive Devices Program to apply for funding for diabetes equipment and supplies for clients requiring insulin; (b) ensure clients have filed their income tax and are receiving their maximum allowable benefits; and (c) connect clients to community support services that may offer assistance with income tax benefits, and purchasing food, medical supplies, or other essentials.

The results of this study suggested that older adults benefit from community support services but were not always directed to them by home-care providers. This represents a gap in provider knowledge of community assets. A scoping review of model designs for system navigation in primary care found that education of persons providing navigation (lay persons and nurses) needed to include training on local community

services (Carter et al., 2018). Therefore, education about the breadth of community support services and how to support older adults to consider such options is essential for those providing home-care services. For example, a strategy would be having a link on home-care providers' electronic devices to 211 Ontario (see <https://211ontario.ca/>)—a free on-line platform and helpline that supports Ontario residents to locate local community and social services—for their reference and to share with their clients.

Implications for Policy and Health-Care Service Delivery

Enacting a person-centred approach and integrated care is challenged by the current organization of home care as a separate silo from community support services, primary care, and the rest of the health-care system, and will require government and policy decision-makers' action to orient the system to persons and their families (Entwistle et al., 2018). Thus, for the health-care system to better support this population of older adults with T2DM and UI, several health care system leadership and policy activities need to occur.

A key finding of this study was that home-care nurses were underutilized in the care of this complex population of older adults with T2DM. Less than one-third (29.5%) of the home-care population received nursing services. This suggests a need for home care to proactively provide nursing services to older adults with MCC, such as those with T2DM and UI, who are at risk of institutionalization, have medical instability, and are experiencing issues that are amenable to nursing intervention. The results from a series of randomized-control trials with older adults receiving home-care services demonstrated that nurse-led health promotion and disease prevention interventions (for health

promotion, falls prevention, stroke rehabilitation and depression) can positively improve quality of life and maintain older adults in the home environment (Markle-Reid et al., 2006; Markle-Reid et al., 2010; Markle-Reid et al., 2011, Markle-Reid et al., 2014).

Furthermore, the older adult participants in this study had been living with UI for a range of 1 to 20 years (7.5 years on average); highlighting the need to provide early nursing support to optimize continence status to prevent complications such as falls, fractures, and premature institutionalization (Chiarelli et al., 2009; Coyne et al., 2013; Wagg et al., 2017). This will require changes to local home-care eligibility criteria regarding nursing services from a task-focus to comprehensive care for clients at risk of negative outcomes.

The nurse participants in this study continued to try to provide comprehensive care for their clients with T2DM and UI despite the challenges in the home-care environment. Enabling nurses to continue to do this work without the system challenges and work-arounds would certainly be facilitated by a system-wide integrated—rather than the current fragmented—care approach. Thus, to change the current home- and health-care system, evidence suggests that strong leadership is required to foster an organizational culture supportive of person- and family-centred care and care integration (Entwistle et al., 2018; Kirst et al., 2017). To promote an integrated health care system, system leaders must develop a shared vision for integration across all sectors of the system, including community and social services (Kirst et al., 2017). While the interprofessional teams themselves, such as home-care providers, must be engaged in the

re-design of their team functions and processes, system leaders will need to support and provide the teams with time to meaningfully develop this work (Kirst et al., 2017).

With the current changes in the Ontario health-care landscape and the introduction of the concept of Ontario Health Teams, this type of culture change and system reorganization could emerge. Service-provider agencies and organizations (i.e., hospitals) have self-mobilized, applied to be considered as candidates for Ontario Health Teams, and are currently developing full applications to submit to the Ministry in October of 2019 (Ontario MOHLTC, 2019b). This redesign could be most helpful for older adults with MCC and their caregivers by ensuring an integrated approach. The vision for the Ontario Health Teams is that clients would receive all their care—previously delivered by different teams in different settings across primary, community, home, acute, long-term, and mental-health care—from one team. For example, in Hamilton, Ontario, the identified partners are diverse and appear to be reflective of a social determinants of health approach in that along with hospitals, primary-care practices, and home-care agencies, organizations such as the Alzheimer Society of Hamilton and the City of Hamilton Healthy and Safe Communities Department are collaborating (Frketich, 2019). Also encouraging from a patient- and family-centered care perspective, is that this potential Ontario Health Team has identified two former cancer-care patients as the co-chairs of the working group (Frketich, 2019). This type of community partner engagement is important to ensure that changes to care provision remain grounded in clients' experiences and produce a redesign plan that is more likely to

reflect the needs of health-care service providers and the clients and caregivers they serve.

Changes to existing policies are also needed to facilitate an integrated, person- and family-centred care and social determinants of health approach for older adults with T2DM and UI. First, the *Home and Community Services Act* (1994), should be modified to include caregivers as eligible for professional services if they are supporting a home-care client themselves. This would enable the nature of their caregiving burden to be assessed by a home-care service provider and treatment offered. Second, this *Act* should also be amended to have a wider definition for the setting of care. For example, a home-care nurse might be the most suitable member of the interprofessional team to participate in hospital discharge care-planning sessions with their client but the *Act* specifies that home-care takes place in the client's home. Additionally, a home-care personal support worker could be the most appropriate provider to accompany the client to a community exercise program that otherwise would not provide toileting support, for example. Third, the Assistance Devices Program of Ontario should add incontinence products as eligible for funding and develop a process for older adults with lower incomes to apply for funding. Fourth, to facilitate home-care providers' access to client health information in existing electronic health records, LHIN contracts with service-provider agencies should change the provider's status to "health information custodians" (Home Care Ontario, 2019). Consideration of this issue of shared electronic health records is required of potential Ontario Health Teams as part of the "digital health plan", which is promising (Ontario MOHLTC, 2019b)

Policy changes will also need to be made related to funding models of the different settings in the health-care system. In order for interprofessional teams to develop relationships, build trust, design protocols for working better together, and review care-planning as a team, they will need the time, and by extension, funding to be able to undertake these activities. In the current LHIN-funded home-care model, service providers are paid by the visit and not for indirect service, such as a team meeting. In the realist review of integrated care programs for older adults, models with salaried staff (including primary-care physicians) were more able to implement an integrated care model than those with staff who were working in a fee-for-service model (Kirst et al., 2017). For the Ontario Health Teams, no additional funds have been provided by the government for this type of collaboration, thus potentially threatening its vision of integrated care (Ontario MOHLTC, 2019b).

Implications for Research

This study has generated implications for future research. To start, the study results provided information on the potential components of an interprofessional complex intervention to care for older adults with T2DM and UI in the home-care context (see Table 1), including comprehensive geriatric assessment, and interventions to target the multiple factors affecting continence (e.g., chronic conditions, social support, function, well-being). The next step would be to share these proposed components and conduct a consensus-building process with multiple stakeholders, such as older adults and their caregivers, home-care nurses, home-care coordinators, interprofessional home-care team members, community support service providers, primary-care providers, specialist

providers (such as, diabetes educators, geriatricians), and policy and decision makers.

The goal of this Delphi-style method would be to review and revise the components and articulate the intervention processes and expected outcomes (McPherson, Reese, & Wendler, 2018; Sidani & Braden, 2011).

As part of this process, the experiences of other home-care providers (such as personal support workers, occupational therapists, physiotherapists) and primary-care providers caring for older adults with T2DM and UI and providing interprofessional collaboration for this population could be elicited. This would be most informative in developing the role responsibilities for the components and processes for collaboration. Further research is warranted to identify and test strategies to enhance interprofessional communication within the home care sector.

The newly articulated intervention could then be subjected to a pilot study to determine the feasibility of implementing the intervention and its preliminary effectiveness. The results of this pilot study could be used to inform the design of a future pragmatic randomized control trial to further test the intervention. For example, a plan to deliver the newly designed intervention could be developed and evaluated within an Ontario Health Team.

Some questions remain that would also benefit from future research exploration. Monitoring of the incidence and prevalence of UI nationally in older home-clients with T2DM could be conducted utilizing the routinely collected interRAI HC data and would be useful to understand the progression of UI in this population over time. Investigation

of the perspectives of ethnoculturally diverse home-care recipients with T2DM and UI is required as the majority of the older adult participants in the qualitative strand of this study were Caucasian. Older adults of certain racial or ethnic groups could face discrimination that would create health inequities not captured in this current study (Solar & Irwin, 2010). Additionally, as found in the qualitative research on the experience of living with T2DM, older adults of different ethnocultural groups had different social, spiritual, dietary, language, and health education needs (Carolan-Olah & Cassar, 2018; Joo & Lee, 2016; Washington & Wang-Letzkus, 2009). A gendered quantitative analysis of the correlates of UI in older adults with T2DM and MCC would also be helpful given that older women were more likely than older men to experience UI in this study and very little research has been conducted with men to understand the relationship between diabetes and UI (Brown et al., 2005). This empirical and experiential evidence would be important to inform tailoring of the complex intervention (Sidani & Braden, 2011).

Strengths and Limitations of the Study

This mixed methods research study had many strengths in the design and execution of the quantitative and qualitative strands, and the mixed methods integration. However, there are some limitations to consider in each strand and the final interpretation. Strengths and limitations of each of the strands have been described in the previous chapters, so a summary will be provided here, as well as discussion of the strengths and limitations particular to the mixed methods integration.

Strengths of the quantitative strand of the study were the use of the standardized and validated RAI-HC data and the very large population-level sample of older home-

care recipients. The RAI-HC instrument has been subjected to rigorous testing and on-going quality improvement (Hogeveen, Chen, & Hirdes, 2017; Landi et al., 2000). In addition, the health outcome scales have been validated against gold standard assessment tools (Landi et al., 2000). Finally, as the RAI-HC is used in clinical practice with all long-stay home care clients, the study participants were not representative of a population but *were* the entire population of older adults with T2DM receiving home care in the study time frame (Morris et al., 2012).

The key strength of the qualitative strand was the consistent application of the principles of interpretive description methodology and the disciplinary relevance of the study in addressing a current nursing practice problem (Thorne, 2016). For example, analytic logic was demonstrated in the clear descriptions of data collection, data analysis, and findings inclusive of participants' quotes (Thorne, 2016). In addition, interpretive authority was maintained by reflexive journaling and the research team's involvement in analysis and conceptualization of the findings (Thorne, 2016).

The core strength of the mixed methods research study was the validity demonstrated by the enactment of the convergent design as proposed and the true mixing and interpretation of the quantitative and qualitative strands (Creswell & Plano Clark, 2018). The mixed methods approach facilitated a more complete and in-depth exploration of the need-services gaps than would have been afforded by either a quantitative or qualitative design alone. The findings from each strand revealed unique and different insights from multiple perspectives. Convergence across the strands strengthened the credibility of the results; and divergence between the strands provided new insights into

the differences in experiences and perspectives between older adults and nurses. Furthermore, the use of the complexity conceptual model ensured integration of the separate strands into a more complete understanding of the complexity of living with T2DM and UI for older adults receiving home care (Evans, Coon, & Ume, 2011). Studying older adults receiving home-care services in both the quantitative and qualitative strands can directly inform home-care in order to promote well-being and function. Thus, these findings are valuable and likely have generalizability and transferability to older home-care recipients in other provinces in Canada and countries with publicly-funded home care.

The quantitative and qualitative strands did have some limitations. In the quantitative strand, not all potential contributing factors of UI are collected in the RAI-HC (i.e., low fluid intake, body mass index, glycemic control, etc.), and this could cause residual confounding. Also, the diabetes disease diagnosis in the RAI-HC includes both type 1 and type 2 diabetes and while the proportion of older adults with type 1 diabetes is small, it would be important clinically to differentiate between the two groups (Morris et al., 2012). The cross-sectional design limited conclusions that could be drawn because a temporal order for factors associated with UI cannot be established.

In the qualitative strand, the main limitation was the lack of ethnocultural diversity. As well, there were fewer men than women in the study sample, although this is consistent with prevalence rates of UI in the literature (Du Moulin et al., 2008). The qualitative strand with nurse participants was limited in that it captured the experiences of home-care nurses in only three LHINs, in one province, and in mostly urban, non-rural

areas. The nurse participants were also very experienced and likely held different perspectives than novice nurses. An overall limitation of the mixed methods study was that not all aspects of complexity were captured in each strand, such as information about community support service use and clients' goals and preferences.

Strengths and Limitations of Conceptual Framework

As described in the results chapters, the use of the complexity model in framing, designing, and implementing the study as well as analyzing the study's results, was immensely useful. The model provided an organizational device to explore complex human experiences in a complex health-care system by guiding exploration of the multiplicity of influencing factors (Evans et al., 2011). Practically, the complexity model was helpful in structuring the interview guides for both older adults and nurses to identify the need-services gap and the factors influencing this gap. In the quantitative strand, the model increased credibility in that the results were both empirically- and conceptually-based. In the mixed methods integration, using the model's definition of complexity as a misalignment between client needs and services, afforded the generation of strategies to address the need-services gap at service- and system-delivery levels (Grembowski et al., 2014).

The authors of the complexity conceptual model have encouraged researchers to work with the model and further test, refine, and expand on the model based on qualitative and quantitative research (Grembowski et al., 2014). Based on this study's findings, interprofessional collaboration should be added as an influencing factor in the health-system component of the model. For older adults with T2DM and UI, the

interprofessional team would include home-care, community support services, primary-care, and specialist-physician providers. While intervention development typically relies on middle-range theories rather than conceptual models to understand the clinical problem, the authors were not aware of any middle-range theories on complexity and MCC to inform this work (Sidani & Braden, 2011).

Conclusions

This mixed methods research study has enhanced current understanding of the complexity of living with T2DM and UI for older adults receiving home-care services. The findings have laid the foundation for the development of a complex and multifaceted intervention to improve this population's health and well-being. Enacting this type of complex intervention in the current home-care system will require system-wide implementation of an integrated model of care delivery that enacts a person- and family-centred care and social determinants of health approach. In Ontario, with policy changes underway that will affect the provision of home care, these findings are timely and relevant to inform care approaches that attend to both client and system complexity related to older adults with MCC.

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Table 1

Joint Display of Mixed Methods Study Results and Intervention Components

Complexity Model Components	NEED-SERVICES GAP Mixed Methods Interpretation		IMPLICATIONS Intervention Components to Address Need-Services Gap
	Convergent	Divergent	
NEED			
Person (chronic conditions, characteristics [age, sex, race, ethnicity, income], values and preferences)	<ul style="list-style-type: none"> • Living with MCC and UI affected level of needs for services and made service delivery very challenging. 	<ul style="list-style-type: none"> • Financial barriers and individual preferences were important influencers of the need for services but were inconsistently considered by providers. 	<ul style="list-style-type: none"> • Conduct comprehensive geriatric assessment. • Detect UI at onset. • Enact person- and family-centred approach to goal setting and care. • Educate client and caregiver on relationship of T2DM and UI and contributing factors to UI. • Intervene to support glycemic control. • Recommend fluid and diet changes. • Educate about, monitor, and prevent complications of diabetes. • Use multiple strategies to treat and manage UI. • Educate and collaborate with PSWs on continence promotion. • Address financial barriers. • Support chronic disease self-management of other chronic conditions. • Manage geriatric syndromes. • Collaborate with primary-care providers.
Social Support (family, other sources)	<ul style="list-style-type: none"> • Older adults were reliant on caregivers and these caregivers experienced burden that negatively affected their ability to continue in caregiving role and influenced older adults' needs for services. 	<ul style="list-style-type: none"> • Nurses sought to mitigate caregiver burden, yet older adults felt their caregivers were not adequately supported. 	<ul style="list-style-type: none"> • Connect caregivers to community support services. • Support caregivers including specific support regarding UI and T2DM.
Health (function, well-being)	<ul style="list-style-type: none"> • Older adults struggled to balance treatments offered for individual chronic conditions 	<ul style="list-style-type: none"> • Older adults emphasized importance of maintaining social activity but this was not a focus for nurses. 	<ul style="list-style-type: none"> • Consider treatment burden with other chronic conditions. • Optimize or support ADL and IADL function. • Support maintenance or enhancement of social activity. • Provide balance and mobility training.

Complexity Model Components	NEED-SERVICES GAP Mixed Methods Interpretation		IMPLICATIONS Intervention Components to Address Need-Services Gap
	Convergent	Divergent	
	with MCC and nurses assessed/treated functional abilities.		<ul style="list-style-type: none"> • Promote physical activity. • Collaborate with OT, PT, and PSW regarding ADL and IADL optimization. • Collaborate with primary-care, specialist-care, and community support services providers.
SERVICES Health Care System (home care, organization of health-care system; availability of electronic health record; education of providers to treat MCC)	<ul style="list-style-type: none"> • Home-care delivery and the larger health-care system was contributing to a needs-service gap for older adults with T2DM, UI, and MCC by not providing professional and supportive services that older adults required. 	<ul style="list-style-type: none"> • Older adults were at risk for adverse outcomes but received very little professional home-care services. 	<ul style="list-style-type: none"> • Utilize nurses to support care of older adults with T2DM and UI. • Facilitate interprofessional collaboration between home-care providers and with other providers in the health-care system. • Identify clients at risk of developing UI or worsening UI by optimizing utilization of interRAI assessments and the care-coordination role. • Implement a communication system for interprofessional collaboration. • Implement a shared electronic health record.
Community Resources (partnerships beyond health-care system, access)	<ul style="list-style-type: none"> • Community resources have potential to positively support older adults to live well with T2DM, UI, and MCC. 	<ul style="list-style-type: none"> • Navigation to community resources is a missed opportunity to provide care and improve health outcomes for older adults. 	<ul style="list-style-type: none"> • Navigate to and coordinate community support services' provision of homemaking, meal preparation, and adult day programs.

Note. ADL = activities of daily living; IADL = instrumental activities of daily living; MCC = multiple chronic conditions; OT= occupational therapist; PT = physiotherapist; PSW = personal support worker; T2DM = type 2 diabetes mellitus; UI = urinary incontinence.