


The Complexity of Living with Diabetes and Urinary Incontinence for Older Adults with Multiple Chronic Conditions Receiving Home Care Services: An Interpretive Description Study

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Abstract

Over 40% 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.

Keywords

diabetes, older adults, urinary incontinence, home care, multiple chronic conditions, complexity, interpretive description, Canada

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Introduction

Urinary incontinence (UI) is a common and burdensome condition among older adults with type 2 diabetes mellitus (T2DM) receiving home-care services. In a cross-sectional study of home-care clients in Canada and Europe, 48% of older adults with T2DM reported experiencing UI (Vetrano et al., 2016). Older adults with UI are at greater risk for depression, falls, fractures, functional decline, and premature institutionalization than those without UI (Coll-Planas et al., 2008; Dugan et al., 2000; Wagg et al., 2016).

T2DM can be understood as multiple chronic conditions 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). Multiple chronic conditions is defined as two or more conditions that require ongoing care and attention and is associated with poor quality of life and functional disability (Gruneir et al., 2016). 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).

This clinical complexity creates challenges intervening clinically and researching UI in older adults with T2DM and other chronic conditions. The relationship between T2DM and UI in older adults is often overlooked. UI is untreated or undertreated in older adults with T2DM, placing them at risk for negative consequences (American Geriatrics Society, 2013; Brown et al., 2005). However, biological evidence shows that the physiological, microvascular, and neurological complications of T2DM impact the continence mechanism and create problems in bladder

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storage, emptying, and cerebral control of the bladder (Daneshgari et al., 2009; Lifford et al., 2005; Sakakibara et al., 2012; Tsui et al., 2018). This translates into difficulties with increased bladder instability or decreased contractility, both of which can cause UI and other lower urinary tract symptoms, such as urgency (Daneshgari et al., 2009; Sakakibara et al., 2012). Additionally, hyperglycemia may lead to polyuria, which contributes to nocturia, urgency, and UI. Older adults with diabetes are also at increased risk of urinary tract infections, which is a common, reversible cause of UI in older adults (Gomez et al., 2011).

With approximately 1.3 million older adults receiving home-care services annually in Canada, UI represents a very common problem in this sector (Better Home Care in Canada Partners, 2016). Home care in Canada 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). Home-care clients in the province of Ontario have become increasingly complex over recent years with greater impairments in cognitive, mood, and functional abilities and higher risk for long-term care placement (Hogeveen et al., 2017). In the province of Ontario, at the time of the study, home-care services were overseen by 14 local health integration networks and care-coordinators, employees of these networks, determined client eligibility for services and coordinated care (Donner et al., 2015). Home care is not mandated as part of the national, universal health care system of Medicare (Baranek et al., 2004). As such, provincial governments have structured home-care provision of nursing, personal support, and other health-care professionals as a mix of public, voluntary, and commercial providers (Baranek et al., 2004). A very small proportion (less than 5%) of provincial health-care funding is spent on home-care services (Wilson et al., 2015). Yet, most older adults want to remain in their own homes, avoid long-term care placement, and will likely require UI care to do so (Better Home Care in Canada Partners, 2016).

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). Participants in a number of studies valued being supported over time by health-care providers who treated them as a person and not a disease, were knowledgeable about diabetes, and helped

them achieve goals that were important to them, such as maintaining independence (Huang et al., 2005; Wilson, 2012; Woodcock & Gillan, 2013).

Qualitative exploration has also been done regarding older adults’ experiences living with UI. These studies found that many 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 et al., 2008; Horrocks et al., 2004; Park et al., 2017; White et al., 2014). Participants also shared that they prioritized issues related to their other chronic conditions over incontinence in short, primary-care visits (Andersson et al., 2008; Horrocks et al., 2004). Thus, participants dealt with UI themselves, sometimes proactively, such as knowing the location of public toilets when out, using product, or performing pelvic floor muscles exercises (Andersson et al., 2008; Horrocks et al., 2004; Park et al., 2017; White et al., 2014). However, many participants managed UI in potentially harmful ways by not leaving home for fear of public accident and restricting fluids (Andersson et al., 2008; Horrocks et al., 2004; Park et al., 2017; White et al., 2014). Participants in one study of self-management experiences of Korean women with UI had received treatments for UI, such as medications or surgery, but these treatments did not resolve their UI (Park et al., 2017). Some participants in two of these studies were receiving home-care services but it is not clear from this body of research how home-care services could support management of both UI and T2DM or how older adults’ self-management and experiences are affected by living with both T2DM and UI (Andersson et al., 2008; Horrocks et al., 2004). 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, multiple methods research study (protocol previously published; Northwood et al., 2019). 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 multiple methods research study also included a qualitative strand exploring how home-care nurses cared for older adults with T2DM and UI and a quantitative strand to determine the prevalence and correlates of UI in this population (Northwood et al., 2020, 2021). This paper presents a unique analysis not covered in the other publications.

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 et al. (2014). In the model, complexity is conceptualized as the gap 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 need-services gap 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 the overall multiple methods study design, develop the topics and questions in the interview guide, and inform the initial “sorting and organizing” phase of data analysis in qualitative analysis (Thorne, 2016, p. 156). In the overarching interpretation, the domains of the complexity model were used to compare and contrast the findings across the strands and comprehensively describe the need-services gap for older home care clients with T2DM and UI. 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 was a PhD nursing student at the time of this study 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 she 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 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 the first author 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 3 of the 14 local health integration networks (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 multiple methods research 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 the first author 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., 2019). 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). Data collection ended when the research team reasonably concluded that enough experiences had been obtained in order to generate a credible interpretive description. 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, 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 et al., 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 the first two authors, 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 research team used several strategies to enhance trustworthiness. First, the team was committed to co-constructing knowledge by authentically interpreting participants’ experiences. As the interviews were all conducted by the first author, review of a selection of transcripts was done by the entire research team. The coding of a number of transcripts was conducted by the second author at different time points during data collection. As well, tables of emerging themes with supporting quotes and participant profiles (individual participant responses to questions collapsed into a one to two page document) were shared and discussed as a team. Second, the team was intentional about creating a credible interpretive description that included commonalities among participants but also highlighted differences (Thorne, 2016). Third, researcher triangulation occurred during regular team analysis meetings where alternate explanations were debated and consensus reached (Thorne, 2016). As the first author was practicing in home care at the time of study, other members of the team would test if her assumptions were related to her own nursing perspective or participants’ experiences. In addition, the first author’s reflexive journaling after interviews and discussions with the research team also strengthened the interpretive authority of the study and allowed her to reflect on unexpected findings. Meeting needs documenting analysis decisions also served as an audit trail. Finally, standards were followed for the reporting of qualitative research (O’Brien et al., 2014).

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.

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%). Most participants were taking insulin (66.7%) as part of their treatment for T2DM.

More than one half (55.6%) of participants were receiving nursing services, about two thirds (61.1%) were receiving personal support worker care, and about one third (33.3%) were receiving both services. One quarter (27.8%) of participants were receiving occupational therapy, and 16.7% were receiving physiotherapy.

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.”

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

*Five participants declined to answer this question.

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 multiple chronic conditions 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 multiple chronic conditions. 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 multiple chronic conditions. 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 multiple chronic conditions 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 personal support worker 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, three of the five 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 personal support worker 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 personal support worker 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 [personal support worker] 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 2 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 personal support workers 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 multiple chronic conditions.

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 personal support worker 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 personal support worker 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 personal support workers. For example, one participant wanted more help with meal preparation, and another with housekeeping. However, due to time constraints, the personal support workers 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 personal support workers 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 personal support worker 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 personal support worker all the nuances of the care they required (05). This male participant, receiving twice-daily support, experienced difficulties with unfamiliar personal support workers:

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 personal support workers enriched their lives and their health. This participant remarked fondly of his primary personal support worker, “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 personal support worker also identified the development of a new pressure injury and advocated for timely nursing treatment. Another female participant detailed how her primary personal support worker 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 personal support worker access through a personal-alert system and found this arrangement exceptional for regularly scheduled care provision and the security of knowing personal support workers 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 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. In addition to UI, some participants also experienced other bothersome urinary symptoms, such as nocturia and frequency. The ability of this population to continue to live at home in the community was threatened by a number of factors from both the older adults' needs and service delivery perspectives: care that was incongruent with participants' goals, needs, and multiple chronic conditions; 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 were not well supported in developing more knowledge and a broader set of 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. Determining the unique needs of older adults for home-care services can be achieved using comprehensive geriatric assessment tools, such as the standardized interRAI home care assessment (Morris et al., 2012). The interRAI home care assessment is used across Canada (including Ontario), Europe, some states in the United States, and the Asia-Pacific Rim (Hong Kong, Singapore, Japan, Australia, New Zealand; Morris et al., 2012). Home-care coordinators using this tool would be prompted to develop a care and service plan to manage UI if the UI clinical assessment protocol triggered (Morris et al., 2008). When the interRAI home-care assessment is used in this manner, evidence from a systematic review found a reduction in hospital admissions and length of stay for older home care clients (De Almeida Mello et al., 2015). However, these client benefits are only realized in home-care agencies working intensively with the interRAI assessment, as noted in a randomized controlled trial in Germany (Stolle et al., 2012). As well, cross-sectional research of American home-care clients found that UI improved with care from a nurse specialized in continence, supporting UI as amenable to intervention in this population (Bliss et al., 2013).

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 multiple chronic conditions 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). This study highlighted the importance of a person-centred—rather than a disease-focused—approach to integrated care. This is in keeping with other evidence that focusing on functional, social, and cognitive capacity is more effective than specific chronic condition management in organizing integrated health care services to meet older adults' needs (de Carvalho et al., 2017). 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 et al., 2008; Dugan et al., 2000; Meneilly et al., 2018; Wagg et al., 2016). Improving UI in this population of older adults certainly should include attending to optimal management of T2DM but as these participants shared, must also consider the impact of other co-existing chronic conditions in the context of older adults' daily lives.

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 (Canadian Institute for Health Information, 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 has identified the economic impact of UI and estimates that an individual with UI spends \$2,100 on incontinence supplies per year (Canadian Continence Foundation, 2014). Conceptualizations of multiple chronic conditions 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. This study provides more evidence of social support as a major influencing factor in mediating the needs of older adults with multiple chronic conditions (Grembowski et al., 2014). 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 (Better Home Care in Canada Partners, 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). Of interesting note, while caregiving is a gendered construct with women disproportionately taking on caregiving roles and experiencing burden, this study instead had many male caregivers and the female participants shared their concerns about the negative impact on their caregivers (Williams et al., 2017).

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 personal support workers, 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. This is an international trend in countries with similar home-care provision to Canada due to many factors, including: demands for services greater than existing funding mechanisms; human resource challenges, including recruitment and retention in the home-care sector; lack of system integration (Farmanova et al., 2019; Ganann et al., 2019; Markle-Reid et al., 2017; Province of British Columbia, 2014).

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 (Better Home Care in Canada Partners, 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 et al., 2017). Also, the clinical management of T2DM and UI must be considered in the context of multiple chronic conditions.

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 multiple chronic conditions should also be included with reference to guidelines for care of older adults with multiple chronic conditions (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 an Ontario 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, similar to processes that exist in the National Health System of the United Kingdom. As well, policies that determine home care eligibility and funding for caregiver respite and flexible work schedules require international examination and improvement to provide better and more integrated services and supports for family and friend

caregiver support (Better Home Care in Canada Partners, 2016; Colombo et al., 2011; 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 multiple chronic conditions. 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 multiple chronic conditions) require further research exploration. As well, a gendered analysis of differences in experience of men and women would be helpful to inform customization of a care approach. 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 multiple chronic conditions 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. Finally, although it is not known definitively that the participants' UI was caused by T2DM but likely influenced by the additive effect of their many conditions, the findings highlight the importance of taking a holistic and comprehensive approach to assessment and treatment of chronic conditions in a home-care population of older adults.

Conclusion

Older adults with UI and T2DM receiving home-care services are also living with multiple chronic conditions. They do not consistently receive home-care services that consider: their unique needs; the complex interplay of UI, T2DM, and multiple chronic conditions; 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 multiple chronic conditions, and attention to the social determinants of health—is needed to improve the quality of life for this population.

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