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## An Exploration of Knowledge Translation Amongst Homecare Providers, Family Caregivers, and Clients

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Graduate Program in Nursing  
A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy  
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AN EXPLORATION OF IN-HOME URINARY INCONTINENCE MANAGEMENT  
KNOWLEDGE TRANSLATION AMONGST HOMECARE PROVIDERS,  
FAMILY CAREGIVERS AND CLIENTS

(Spine title: In-home Urinary Incontinence Management Knowledge Translation)

(Thesis format: Manuscript)

by

Lynn Jansen

Graduate Program in Nursing

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies  
The University of Western Ontario  
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THE UNIVERSITY OF WESTERN ONTARIO  
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An Exploration of In-home Urinary Incontinence Management Knowledge Translation  
amongst Homecare Providers, Family Caregivers and Clients

is accepted in partial fulfillment of the  
requirements for the degree of  
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## ABSTRACT

The aim of this two-phased investigation was to enhance understanding of urinary incontinence (UI) knowledge translation (KT) to inform *how* UI management knowledge might be translated within in-home nursing practice and family caregiving. Such knowledge might inform and support family caregivers' and older homecare recipients' UI care efforts. Although UI can be managed conservatively, it is a principal reason for the breakdown of family care and care recipient admission to long-term care. As well, Canadian families sustain annualized in-home UI expenditures of \$2.6 billion. Research has afforded little insight into family caregivers' experience of KT and the process of in-home KT for UI management.

The first study used a hermeneutic phenomenological approach (Van Manen, 1997) to explore family caregivers' experience of UI KT. Data were collected from in-depth interviews with a purposive sample of family caregivers (n=4) and analyzed with immersion and crystallization interpretive methods. Caregivers' experience of KT transpired as a social interaction of working together/not working together that was characterized by: *compromising/not compromising, appreciating/not appreciating, understanding/not understanding, encouraging knowledge seeking/impeding knowledge seeking, listening/not listening, and trusting/not trusting*. Continuity of the paid providers of homecare and adequate time to develop working relationships as well as many personal attributes all contextualized working together/not working together, thereby entering into the experience of KT.

The phase two grounded theory study explored the enactment of in-home KT. In-depth interview data were collected from a theoretical sample of 23 family caregivers, homecare recipients, and homecare providers. Constant comparison and Glaser's analysis

criteria were used to create the substantive theory of *Translating Knowledge Through Relating*. Findings illuminated how intersubjectivity and bi-directional relational interactions are interlinked in and essential to translating in-home care knowledge which is largely tacit and experiential in nature. Insights afforded understandings about how relational practice is necessary to foster mutual and equitable social construction of KT. The practical application of ‘*Translating Knowledge Through Relating*’ may constitute an important component of promoting health as a resource for everyday living with UI and ultimately, decrease UI-related expenditures and long-term care admissions.

Keywords: Social interaction, knowledge translation, home care, family caregivers, nursing practice, relationships

## CO-AUTHORSHIP STATEMENT

Members of my dissertation advisory committee, Dr. Carol McWilliam, Dr. Dorothy Forbes, and Dr. Cheryl Forchuk contributed to the chapter manuscripts contained herein through their advisement on the conduct of this exploratory research and to the peer review process. This advisement promoted interpretive findings that reflected participants' experiences and constituted a coherent, cohesive conceptualization of family caregivers' experience of urinary incontinence knowledge translation and the social enactment of 'Translating Knowledge Through Relating' within the in-home care context.

## DEDICATION

In loving memory of my daughter-in-law Dr. Caroline Kosmas.

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## CHAPTER ONE

### INTRODUCTION

Urinary incontinence (UI), defined as the unintentional excretion of urine (Abrams et al., 2003), is a principal cause of the collapse of informal in-home elder care arrangements and care recipient admission to long-term care (Farage, Miller, Berardesca, & Maibach, 2007; Thomas et al., 2004). Forty-six percent of elderly home care recipients experience symptoms of UI (Du Moulin, Hamers, Ambergen, Janssen, & Halfens, 2008) and this is anticipated to increase with an aging population (Canadian Continence Foundation, 2007). Urinary incontinence can be addressed through conservative treatment and continence promotion (Cheater, 2009, Fader, Bliss, Cottenden, Moore, & Norton, 2010). However, unpaid caregivers who provide personal, social and health care for 98% of older adult family members and friends receiving home care services (Canadian Institute for Healthcare Information [CIHI], 2010), may lack knowledge about continence promotion and management (Jansen & Forbes, 2006). Caregivers, herein referred to as family caregivers, have significant problems managing UI (Brittain & Shaw, 2007).

Yet within the in-home context, little is known about what knowledge family caregivers may have (Crooks, Williams, Stajduhar, Allan, & Cohen, 2007; Schumacher, Stewart, Archbold, Dodd & Dibble, 2000) or require to manage continence successfully (Shimanouchi, Kamei, & Hayashi, 2000) and thereby avoid these devastating problems. Furthermore, knowledge requirements may vary according to the values, expectations, and context of various individuals and groups (Bowen, Erickson, Martens, & Crockett, 2009; Davies, Nutley, & Walter, 2008; Dickinson, 2005), as well as with types of knowledge, such as experiential and tacit 'how to' knowledge (Ferlie, 2005; Scott, Seidel,

Bowen, & Gall, 2008), and research evidence (Lomas, 2005). Given these uncertainties about family caregivers' experience and involvement in the process of KT, KT is inadequately informed.

Knowledge translation is a process that includes the creation, exchange, enactment, and application of knowledge within an interactive context to promote health (Canadian Institutes of Health Research, 2009). The KT process is informed by pre-existing personal knowledge, experiential learning, and preferred sources of information, all often linked to social interaction (Nutley, Walter, & Davies, 2003).

How family caregivers may engage in KT approaches (Mahoney, Trudeau, Penyack, & MacLeod, 2006) for UI interventions is not known. Enhanced knowledge and understanding of family caregivers' experience of and involvement in the process of KT may inform strategies for UI management. Not only are both client and family caregiver health ultimately undermined by the strain of unsuccessful UI management (Brittain & Shaw, 2007; Cassells & Watt, 2003; Raiwet & Phillips, 2001), but also UI results in annualized expenditures for families of \$2.6 billion in Canada (Canadian Continence Foundation, 2007) and \$14.2 billion in the United States (Hu et al., 2004).

### **Background and Significance**

Nearly 50% of older home care recipients experience UI (Du Moulin et al., 2008), and this is anticipated to increase with an aging population (Canadian Continence Foundation, 2007). Persons with symptoms of UI can experience skin breakdown, falls, urinary tract infections, and social isolation (Engberg, Kincade, & Thompson, 2004; Farage et al., 2007; Garcia, Crocker, & Wyman, 2005). Family caregivers of those with UI also experience isolation and stress as they increasingly confront the responsibility for UI management at the micro level of in-home care (Brittain & Shaw, 2007).



## Contextual Factors

**Macro Societal Level.** Contextual factors create several challenges to supporting optimal caregiving for people with UI. Due to policy issues at the societal (macro) contextual level, care providers, defined as in-home paid professionals and personal support staff, often are not able to provide family caregivers with the KT support they need to assume caregiver responsibilities (Jansen et al., 2009). Societal level policy factors, which underpin the individual (micro) level context for in-home UI caregivers and paid care providers, include the shift of acute and chronic facility-based care to community settings (Crooks et al., 2007; Romanow, 2002), creating heavy caseloads for in-home care providers, and the lack of financial resources to implement and sustain a community-based health and social care infrastructure that can service these increased caseloads (Health Council of Canada, 2008; McAdam, 2000). Lack of inclusion of home care in the Canada Health Act also has resulted in inconsistent home care services across Canadian Health Regions (Canadian Healthcare Association, 2009; Manning, 2004), creating further imbalances between service demand and supply, particularly for those requiring longer term supportive care.

**Meso Team Level.** At the group, organizational, and team practice (meso) contextual level, challenges to supporting optimal caregiving have been associated with per visit funding formulas that do not provide time for in-home paid care providers to spend with clients and family caregivers for KT (Jansen et al., 2009). Inconsistent assignment of care providers (Forbes et al., 2008; Jansen et al., 2009) and provider turnover associated with employee recruitment and retention issues (Canadian Home Care Association, 2007) also have been linked to the lack of educational guidance

provided to meet family caregivers' needs for knowledge enabling them to manage in-home eldercare (Forbes et al., 2008; Forbes & Neufeld, 2008; Guililand & Busch, 2001).

**Micro In-Home Level.** At the individual in-home care (micro) contextual level, further challenges impede in-home caregiving and opportunities for paid home care providers and family caregivers to engage in KT. The stress associated with the demands of in-home elder caregiving (CIHI, 2010) may contribute to the lack of motivation to engage in KT, specifically for the management of UI (Colling, Owen, McCready & Newman, 2003; Gallagher & Pierce, 2002). The individual who experiences UI may not initially disclose that they experience this problem because of the stigma associated with it (Hayder & Schnepf, 2010; Wyman, 2003). Thus, considerable effort may be required by family caregivers and paid care providers to assist the care recipients with disclosure of their UI symptoms and KT needs for continence management. In addition to the limited knowledge that family caregivers may have about continence promotion (Jansen & Forbes, 2006), paid care providers may believe that UI is a consequence of aging and that continence interventions cannot address UI symptoms (Dingwall, 2008; Mason, Newman & Palmer, 2003; Mason & Tully, 2002). Overall, many facets of the context of in-home care present challenges that undermine UI KT for family caregivers.

**Research at the Macro Societal Level.** Research to date affords limited understanding to inform the contextual factors associated with family caregivers' experience and process of UI KT. At the societal (macro) level, continence promotion research has not explored how policy is related to the individual in-home UI care context (Cheater, 2009; Department of Health, 2001) or how policy has contributed to the inability of the health and social care systems to address family caregivers' needs for

education and guidance with regard to the UI family caregiving role. Little understanding exists of how the KT process for UI caregivers may unfold in diverse home care settings.

**Research at the Meso Team Level.** At the group, team, and organizational (meso) level, research has informed clinical practice guidelines (CPGs) for use by professionals in acute and long term care settings (Engberg et al., 2004; Newman, 2009). Assumptions that traditional didactic evidence-based approaches for continence promotion will be adopted in community-based settings (Roe & Moore, 2004) have not been explored. The need to increase understanding of the experience of KT within the unregulated workforce (Estabrooks, 2004; Estabrooks, Squires, Cummings, Teare, & Norton, 2009) and in long term care settings (Berta et al., 2005; Rycroft-Malone et al., 2009) have received emphasis recently. However, to date, research to inform the team and organizational (meso) level factors associated with in-home UI KT has received little attention.

**Research at the Micro In-Home Level.** The limited UI research conducted at the in-home care (micro) level has focused on: a) family caregivers' experience of providing UI care (Cassells & Watt, 2003; Gallagher & Pierce, 2002; Upton & Reed, 2005), b) interventions with UI CPGs such as assessment and bladder training protocols that can support effective and conservative UI management (Newman, 2009; Ostaszkiwicz, Chestney, & Roe, 2010; Roe & Moore, 2004), and c) content knowledge, that is, the explicit nature of what family caregivers know about health conditions and clinical guidelines (Colling et al., 2003; Schumacher et al., 2000). Family caregivers' "tacit understanding" (Wrubel, Richards, Folkman, & Acree, 2001) or 'know how' knowledge as a form of UI care knowledge has not been explored within in-home contexts (Schumacher et al., 2002). Research has not attended to the exploration of

factors that may enter into family caregivers' use of research evidence at the individual (micro) contextual level.

**Theoretical and Empirical Insights.** Theoretical (Brown & Duguid, 2001; Dopson & Fitzgerald, 2005; Gherardi & Nicolini, 2000; Graham et al., 2007; Kitson, 2009) and empirical insights regarding KT (Estabrooks, Chong, Brigidear, & Profetto-McGrath, 2005; Estabrooks, Midodzi, Cummings, Wallin, & Adewale, 2007; McWilliam, Kothari, Kloseek, Ward-Griffin, & Forbes, D., 2008; McWilliam et al., 2009; Stetler et al., 2006) suggest that family caregivers' experience of KT might best be understood from a social interaction perspective. Knowledge translation frameworks such as PARIHS (Promoting Action on Research in Health Services) (Kitson, Harvey & McCormack, 1998; Kitson et al., 2008; Rycroft-Malone, Harvey, Seers, Kitson, McCormack & Titchen, 2004) use theoretical social process perspectives to study factors associated with knowledge use. A key assumption of the PARIHS framework is that KT evolves through an individual's experience with different types of knowledge, social interactions, and the cultural context of work (Cummings, Estabrooks, Midodzi, Wallin, & Hayduk, 2007). Research also suggests that health care team and organizational facilitators of KT include face-to-face communication, workplace peer relationships, and reflection on and mutual valuing of knowledge (McWilliam et al., 2008; 2009; Mitton, Adair, McKenzie, Patten, & Perry, 2007).

Overall, these social process perspectives may expand understanding of the application of KT Theory and the context of knowledge use in the provision of care. However, little attention has been given to how UI care and UI knowledge-sharing approaches may arise within family caregiver, care recipient, and paid care provider interactions (Gallagher & Pierce, 2002). In addition, theoretical social process

perspectives based in the organizational and professional KT literature (Cummings et al., 2007; Estabrooks, et al., 2007; McWilliam et al., 2003; Scott et al., 2009) have not been applied to the study of family caregiver KT within in-home settings. We do not know if these social process perspectives are applicable to in-home caregiver KT.

### **Statement of Thesis Problem**

We have limited knowledge of family caregivers' experience of KT and how policy contexts, social interactions, and various knowledge forms enter into KT processes between and among in-home professionals, personal care workers, unpaid family caregivers, and those receiving UI care or how such KT processes unfold. Thus, limited understanding exists of *how* UI management knowledge might be translated to inform and support family caregiver efforts to address the challenges of providing UI care. Exploratory research is needed to enhance understanding of UI KT in the home care context.

### **Statement of Thesis Purpose**

The overall aim of this two-phased investigation was to enhance understanding of urinary incontinence (UI) knowledge translation (KT) to inform *how* UI management knowledge might be translated within in-home practice. Such knowledge might inform and support family caregivers' and older home care recipients' efforts to address the challenges of providing UI care. The first study explored family caregivers' experience of KT related to continence management. The second study explored the process of KT between and among paid care providers (such as professional nurses and unregulated care providers), unpaid family caregivers, and care recipients in the context of these challenges. The research question for study one was, 'What is the family caregivers' experience of UI knowledge translation?' The research question for the second phase of

the study was, ‘How do paid home care providers, family caregivers and clients enact UI KT within the context of in-home care?’

Ultimately, findings from both of these studies may assist in: a) understanding family caregivers’ experience of KT, b) development of substantive theory to advance understanding of how to go about the process of KT among paid providers, unpaid family caregivers, and care recipients, c) improved continence care management for the clinical and social problem of UI, d) development of broader KT strategies for application in family caregiver settings, and e) development of continence health promotion policy to support the prevention of associated UI costs and long term care admissions.

### **Overview of Chapters**

The integrated article format approved by the University of Western Ontario has been used to organize this thesis. A review of the literature is provided in Chapter Two. Chapter Three presents the study methodologies and methods used to conduct the research investigations. Chapter Four presents a phenomenological study, which explored family caregivers’ experiences of KT and Chapter Five presents a substantive theory of the process of KT between and among paid home care providers, family caregivers, and home care recipients to promote the management of UI. Chapter Six presents contributions to the research literature and implications for in-home service delivery policy, practice, education, and research relevant to family caregivers’ experience of KT and the social interaction process of KT.

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## CHAPTER TWO

### LITERATURE REVIEW

#### Introduction

The aim of this review of the literature was to critique research studies relevant to the investigation of family caregivers' experience of KT and its enactment within an in-home setting. The ultimate purpose of the review was to inform understanding of what knowledge gaps exist regarding family caregivers' experience of KT and the process of KT between and among home care providers and care recipients to manage in-home UI care.

The online databases of CINAHL, Medline, Embase, Social Work, ERIC, Psych Info and the Cochrane Library were searched for articles published in the English language during the years of 1982 to 2011. Nine search terms were used to generate articles relevant to the history and processes of KT: knowledge transfer, knowledge translation, knowledge development, health knowledge, research utilization, knowledge utilization, knowledge utilization interventions, evidence-based practice, and diffusion of innovation. Search terms used for the next stage of the literature search included: professional practice, nursing practice, nursing care, rehabilitation nursing, respite care, community care, clinical practice guidelines, organizations, community-based in-home knowledge transfer/translation, in-home evidence-based practice, and aging emotional support. As the search became more refined, another search of the databases combined the following concepts: family caregivers, unregulated home care workers, nursing care relationships, inter-personal relations, social interactions, continence health promotion, urinary incontinence, home care work culture/home care context, socio-historical, health



promotion, and empowerment. Manual searches were conducted of the reference lists of all retrieved articles included in the literature review.

Fourteen published research studies were selected as providing insights to inform family caregiver KT and the gaps associated with caregiver KT of UI promotion and management techniques. No definitions or references related to KT were found within the in-home family caregiver and paid care provider interaction literature. No studies were found that explored the experience or process of in-home family caregiver KT specifically for continence promotion and management. Three major themes regarding the investigation of family caregivers' experience of KT within an in-home setting emerged from the literature review.

### **Home Care Providers' and Family Caregivers' Role Enactment within a Social Interaction Context**

The first theme was paid home care providers' and family caregivers' role enactment within a social interaction context relevant to KT for in-home eldercare. Three studies (Benzein, Johansson, & Saveman, 2004; Guberman, Lavoie, Pepin, Lauzon, & Motejo, 2006; Ward-Griffin, 2001) revealed that nurses perceived their role as that of the expert provider with expectations that family caregivers would provide care and receive in-home education to enable eldercare. In a descriptive qualitative study, Benzein et al. explored nurses' (n=5) beliefs about families in home care and found that when families were perceived as a resource, that is, receptive to in-home education, nurses enacted their role by inviting family caregivers to share their concerns and questions about care with them. But when families were perceived to be a burden, that is, resistive to the provision of eldercare, nurses provided expert prescriptive information about in-home care. This research did not address family caregivers' experiences with in-home professional

teaching and KT for UI management or how they might perceive family caregivers' roles or those of paid care providers.

Participants in a multi-case study that explored home care practitioners' (n=55) perspectives of family caregivers' roles (Guberman et al., 2006) perceived that the role of a family caregiver included the responsibility for in-home eldercare and instrumental task-oriented care. Thus, these practitioners felt that family caregivers required instruction and teaching from professionals to facilitate their performance of instrumental skills. While the findings from this study revealed that paid care providers clearly saw a need for KT, their role enactment focused on task-related instruction. As in the investigation by Benzien et al. (2004), family caregivers' perspectives on in-home professional teaching were not addressed. However, Ward-Griffin (2001) explored in-home roles and relationships of family caregivers and paid providers (n=23 nurse caregiver dyads) and illuminated family caregivers' KT experience as one of social interaction with expert care providers. Study findings from this critical ethnographic study revealed that role conflict evolved from the blurring of roles and expectations between family caregivers and paid care providers within the 'public' domain of home care and the 'private sphere' of in-home settings. Ultimately, in-home care was transferred to the family caregivers through the prescriptive teaching techniques of the paid care providers.

Conversely, two qualitative studies found that family caregivers engaged in the role of teaching providers (Heinrich, Neufeld, & Harrison, 2003; Sims-Gould and Martin-Matthews, 2010) to optimize in-home care. The first study (Heinrich et al., 2003), a secondary analysis of 62 interviews (n=20 female caregivers), uncovered a lack of professional understanding of family caregiving needs and expectations that created

difficulty for family caregivers in applying professional care information. The second study (Sims-Gould and Martin-Matthews, 2010) discovered that family caregivers (n=52) assumed a collaborative in-home care role with paid providers and a teaching and instructing role with new in-home care providers who were not familiar with the in-home care required for their family member. However, this study did not elaborate on how teaching and instruction transpired between the family caregivers and paid care providers.

These studies of role enactment relevant to KT for in-home elder care suggest that professional role enactment of task-related instruction and expectations of family caregiver involvement may be factors in family caregivers' experience of KT. Findings also reveal that family caregivers ascribe the same role expectations to themselves, although describing more proactive collaborative roles with paid care providers.

### **Home Care Providers' and Family Caregivers' Experiences and Expectations of KT**

Family caregivers' experiences and expectations of KT was the second theme from the literature review; however, these studies have not addressed family caregivers' experiences and expectations of UI KT. Van den Brink's (2003) ethno-nursing study used descriptive analysis to compare nurses' (n=9) and Turkish family (n=52) caregivers' KT preferences. A key finding of the research was that family caregivers may refuse to use assistive devices if home care education is provided in a prescriptive, didactic way that is not congruent with the family's desire to work and learn through collaboration with providers.

A descriptive exploratory study of family caregivers' knowledge-seeking experience with professionals (Goldschmidt, Schmidt, Krasnik, Christensen, & Groenvold, 2006) and a descriptive analysis within a randomized controlled trial (RCT)

of a coaching intervention on pain management (Schumacher et al., 2002) focused on the ability of the professional to listen to family caregiver concerns. Study findings revealed that when family caregivers were listened to, they: a) perceived professional recognition of their expertise and knowledge base, and b) felt that they were able to share knowledge and suggestions that assisted with shared care planning with the professional. Findings from these two studies suggest that ongoing education and professional problem-solving with family caregivers may be required to support the implementation of in-home interventions. A key challenge related to caregivers' experiences of knowledge-sharing was that one-time provision of didactic teaching was not perceived to be effective. These studies illuminate the KT expectations and challenges that family caregivers experience in relation to complex in-home care, but have not addressed family caregivers' experiences with in-home professional teaching and KT for UI management or interacting with paid care providers to share UI knowledge.

In summary, research from studies regarding family caregivers' experience and expectations of KT has identified an apparent ineffectiveness of professionals' didactic teaching techniques in meeting the KT needs of family caregivers and in creating family caregivers' positive experience of knowledge-sharing and problem-solving with these paid providers to inform eldercare. Findings to date suggest that family caregivers expect care providers to be attentive to their concerns and recognize family caregivers' knowledge of in-home care. However, these findings have not been applied to the study of family caregivers' experience of KT for in-home care for persons with UI. These study findings in part inform caregiver KT; however, further exploratory study is required relevant to the family caregivers' experience and expectations of UI KT.

## **Home Care Providers' Sharing of Knowledge and Information with Family Caregivers and Care Recipients**

The third theme from the literature review focused on research informing paid care providers' sharing of knowledge and information with family caregivers and care recipients. This set of sub-studies included two randomized control trials that tested in-home interventions (Huang, Shyu, Chen, Chen, & Lin, 2003; Markle-Reid et al., 2006). Findings from an investigation of a behavior assessment and management intervention (Huang et al., 2003) demonstrated a significant improvement in the behavioral outcome of dementia clients and care 'efficacy' for dementia family caregivers. Markle-Reid et al. (2006) found that health promotion education provided to home care clients and their family caregivers by nurses was linked to a significant decrease in care recipient depression and an improved ability of family caregivers to access health care system services. Although both of the interventions tested in these studies were premised on a partnering approach, the researchers did not articulate how partnering was enacted.

A qualitative study (Mahoney, Trudeau, Penyack, & MacCleod, 2006) within the intervention arm of a RCT (130 in-home visits to 42 care recipients/family caregiver dyads) provided an intervention encompassing the 'teaching, role modeling, and coaching of bathing' and employed individual case review, reflective journaling by the family caregiver, and methods of observational study of family caregiver and care recipient interactions on bathing care. Study findings revealed that: a) direct observation of family caregiver and care recipient interactions during bath time can enhance the home care providers' knowledge of the family caregivers' and care recipients' bathing experience, b) home care provider and family caregiver knowledge-sharing can occur to co-create an approach to the bathing process, and c) receipt and enactment of care information by the

family caregiver may be affected by hearing loss, discomfort associated with providing personal care to a parent, and a previous negative or positive bathing experience. In addition, family caregiver practice sessions may enhance in-home application of research evidence. While findings suggest a few strategies and issues relevant to KT, questions about KT, particularly KT relevant to UI management, have not been investigated.

Findings from two quasi-experimental studies, which were focused on transfer of content on in-home UI management by professionals providing care to family caregivers, suggested that this approach to KT was effective in promoting caregivers' knowledge application of UI management (Bear, Dwyer, Benveneste, Jeff, & Dougherty, 1997; Colling, Owen, McCready, & Newman, 2003). Colling et al. (2003) demonstrated significant improvement of family caregiver burden, and client-related UI symptoms, care, and costs as compared to the control group outcomes (intervention group = 34 dyads; control group = 25 dyads). However, the family caregivers were not always able to follow instructions provided due to other physical and psychological demands of caregiving. Further family caregiver consultation was recommended to inform approaches to in-home UI KT.

Bear et al. (1997) conducted a quasi-experimental study to investigate the effectiveness of a bladder training intervention for 30 older adult women with 16 in the intervention group (14 clients and two caregivers) and 14 in the control group (13 clients and one caregiver). Although the study results suggested that the intervention was effective in promoting knowledge application of UI management by the family caregivers, this investigation focused on measuring the effectiveness of knowledge transfer and knowledge-sharing actions of only the paid home care providers.

Finally, in a case study by Adkins and Mathews (1997), one spouse caregiver was instructed by the researcher on the use of prompted voiding to promote continence in the family member with dementia. Pre and post study continence pad weights indicated that a significant reduction in weights occurred at 19 days post measure, suggesting that the intervention was effective in achieving UI management knowledge application by the in-home family caregiver. Results from the latter three studies suggest the effectiveness of one KT approach, namely in-home teaching. However, these investigations focused on the knowledge transfer and knowledge-sharing actions of only the paid care providers. No description was provided of the specific KT experiences, processes or educational approaches used by the nurses or family caregivers' KT experience.

### **Research Gaps Identified in the Literature and**

#### **Directions for Further Investigation**

Research findings to date suggest that very little is known about the family caregivers' experience of KT between and among family caregivers, care recipients, and paid care providers to address UI symptoms. Research that has focused on knowledge-sharing and/or transfer approaches from home care providers to family caregivers has revealed that this unidirectional transfer informs the application of evidence-based approaches for in-home care. The limited research conducted on family caregiver-related KT suggests that family caregiver learning and skill practice sessions coached by home care providers, and providers' sharing of their specialized care knowledge with family caregivers may play a role in how knowledge is formed and enacted within an in-home context. In addition, family caregivers expect that their practice and experiential knowledge will be recognized and incorporated within in-home KT and home care planning for the care recipient. Both paid care providers' attentiveness to their concerns

and experiential knowledge have been found to promote family caregivers' application of care protocols to in-home care. However, the majority of family caregiver KT research has been limited to the study of the transfer of paid care providers' eldercare knowledge to in-home family caregivers. Prescriptive educational approaches based on paid care providers' perceptions of the family caregiver's in-home role are often used by professionals in KT efforts. But the literature does not provide an extensive account of how in-home paid provider and family caregiver social interactions inform the process of family caregiver KT.

We have sparse information about the family caregiver's experience of KT or how KT transpires for family caregivers. We require increased understanding of the family caregiver's experience of KT and the KT process to develop approaches for UI in-home management if we are to optimize approaches for UI in-home management. Further in-depth phenomenological investigation is needed to uncover family caregivers' experiences of KT, and subsequently, grounded theory research is needed to explore how family caregivers, paid providers, and clients together socially construct KT.



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## CHAPTER THREE

### METHODOLOGIES AND METHODS

The studies undertaken as part of this dissertation aim to enhance understanding of urinary incontinence (UI) knowledge translation (KT) to inform *how* UI management knowledge might be translated within in-home nursing practice and family caregiving. Such knowledge might inform and support family caregivers' and older homecare recipients' UI care efforts. The methodologies and methods used to meet these aims are presented separately for studies one and two of the dissertation, following an overview of the context of these studies and declaration of self in front of text.

#### Study Context

This investigation was conducted within a south central rural home care setting of one of the 12 health regions in Saskatchewan, namely the Health Authority Board that is accountable for the health services provided to the 56,000 residents of this region. The health authority receives a global funding envelope for allocation across all hospital, continuing care, and long term care services, administering these resources within the parameters of three different collective agreements for home care service staff. Home care, a sub-service of continuing care, is provided to 2,500 clients through an integrated single point of access model for team-based continuing care services. Home care services include: needs assessment and care coordination, home nursing, home health aide services, volunteer services, physiotherapy, occupational therapy, palliative care, respite, intravenous therapy, and Meals on Wheels. Home care team members (nurses, physiotherapists, home health aides, social workers, case managers, and occasionally, physicians) are represented on regional and provincial care, human resource, financial,

and information management quality improvement teams to facilitate evidence-based care and service. The health region is committed to the inclusion of caregivers and clients in team-based quality improvement initiatives to increase the quality of life of those who experience UI, and ultimately, to reduce long-term care admissions and the costs associated with UI management. Thus, the health authority that comprised the context of this investigation was committed to working with the researcher to explore KT related to the provision of in-home UI care for an older adult.

### **Declaration of Self in Front of Text**

The intent of reflexivity in interpretive research is to promote authenticity through description of how the researcher's values, assumptions, experience, and knowledge enters into the interpretation and understanding of the study findings (Todres & Wheeler, 2001). Conscious awareness of my own motives in this investigation as presented herein may assist me in better attending to this investigation of UI.

I am a mature graduate student who brings a diverse community and long term care practice and administrative background to this dissertation study. I became interested in the topic of KT while functioning as a team facilitator to promote Quality Improvement (QI) and Regionalized Health System Accreditation initiatives within rural health care settings. Extensive health system time and resources were often dedicated to the QI and accreditation team efforts undertaken to foster clinical practice pathway implementation. However, I felt that paid care providers had little knowledge and understanding about older clients' and families' health care experiences and thus, seldom incorporated the experiences and perspectives of these care recipients into health service planning and evaluation. I also found that it was very difficult to promote the application

of clinical pathways in traditional facility and emergent community elder care settings to the in-home context.

My interest in the topic of UI developed during my time as a Director of Care and later as a staff nurse in provincial long-term health and social care facilities. Older adults who were admitted to these facilities often presented with symptoms of UI. Family caregivers of these older adult family members frequently stated that the long-term care admission of their family member was underpinned by challenges with in-home UI management. As health care providers, we had little knowledge of family caregivers' in-home experience with UI care and whether or not the application of UI clinical guidelines and/or other in-home care knowledge could promote UI management and ultimately, prevent long-term care admissions.

Upon entering graduate school, I began to reflect on why it was challenging to implement clinical pathways in varied health care settings and why health service planning tends to negate the experiences and perspectives of health care recipients. To inform approaches to UI management as part of my Master of Nursing studies, I pursued a psychometric evaluation of a differential in-home UI clinical assessment instrument. I then became interested in understanding family caregivers' experiences of KT and how their involvement in processes of KT between and among care providers and care recipients might, if at all, inform in-home KT interventions. Specifically, I wanted to investigate how family caregivers' experience of learning and exchanging knowledge of UI care management might enter into a community-based continence promotion intervention for older adults. Given an aging Canadian population and the essential in-home care provided by family caregivers, I continue to feel that it is imperative to promote research that can enhance understanding and provide insights about caregivers'

experience of KT so that KT interventions are aligned with the experiences and needs of family caregivers and in-home care recipients.

## **Study 1**

### **Statement of the Problem**

Research suggests that family caregivers may lack knowledge about in-home continence promotion for elderly care recipients (Jansen & Forbes, 2006). To date, research affords little insight into our understanding of family caregivers' experience of KT, and specifically, their experiences with the process of translation of UI management knowledge to facilitate continence promotion for in-home care recipients. Thus, limited understanding exists of *how* UI management knowledge might be translated to inform and support family caregivers' efforts to address the challenges of providing UI care. Exploratory research is needed to enhance understanding of family caregivers' experience of KT.

### **Statement of Purpose**

The aim of this study was to explore family caregivers' KT experience related to the management of continence in elderly care recipients. Such knowledge might inform *how* UI management knowledge might be translated within in-home nursing practice and family caregiving and support family caregivers' and older homecare recipients' UI care efforts. The research question was: 'What is the family caregivers' experience of UI knowledge translation?' Ultimately, illumination of family caregivers' experience with UI KT may assist in: a) understanding of family caregivers' experience of KT, b) development of substantive theory to advance understanding of how to go about the process of KT among paid providers, unpaid family caregivers and care recipients, c) improved continence care management for the clinical and social problem of UI, d)

development of broader KT strategies for application in family caregiver settings, and e) development of continence health promotion policy to support the prevention of associated UI costs and long term care admissions.

### **Study Design**

A hermeneutic as opposed to a transcendental descriptive phenomenological approach (McWilliam, 2010) was used to investigate caregivers' experience of UI KT. Hermeneutics has as its aim the interpretation of phenomena to uncover hidden meaning (Mackey, 2005; Schwandt, 2000). The hermeneutic phenomenological approach is premised on the belief that phenomenological understanding is intersubjectively constructed. Hence, the researcher's presence and participation shapes the lived experience that is being investigated (Golomb, 2002; McWilliam; 2010; Raynova, 2002). As it is ontological rather than epistemological in its orientation (Van Manen, 1997), the hermeneutic phenomenological approach is congruent with the study of contextualized data about the human experience of KT and the intersubjective nature of knowledge as co-constructed by the researcher and participant (Lopez & Willis, 2004). As well, hermeneutic research is premised on assumptions that the world is dynamic and constantly changing, facts and values are intertwined, and knowledge is historical and situated in context. Phenomenology is not guided by a priori theory, as it is based on the premise of discovering and understanding a phenomenon, often phenomena about which there is little published literature. These attributes render hermeneutic research particularly well suited to the investigation of KT through social interaction.

### **Recruitment and Sampling Strategy**

From a database of home care service recipients and family caregivers in the selected region, case managers and/or home care nurses identified potential English-

speaking family caregiver participants who provided in-home UI care to older family care recipients. Family caregivers were approached by home care case managers, who provided letters of information outlining the purpose of the study and the parameters of participation (Appendix A). The case managers then requested consent from caregivers to provide their name and telephone number to the researcher, who then contacted the family caregivers, further explained the study, and requested formal informed consent for participation (Appendix B).

Purposive sampling of potential participants (Patton, 2002) was undertaken by the researcher to select family caregivers with varied educational backgrounds, age, gender, experience with UI care, and problems with UI management. This sampling strategy promoted the appropriateness of data (Morse, 1991) for capturing the experience of KT for the diversity of in-home caregivers who provide UI care to elderly care recipients. The richness of the data obtained through the phenomenological approach allowed for small numbers of informants (MacDougall & Fudge, 2001). Recruitment and sampling of participants ceased when theme saturation was achieved, that is, when no new information on family caregivers' experience of UI KT was uncovered, and insights and understandings adequately answered the research question (Morse, 1991).

Ultimately, four family caregivers (three females, one male) participated in the study. These family caregivers were the spouses or adult children of the home care recipients, ranged in age from 63 to 86 years ( $\bar{x} = 76$  years), and lived with the care recipient or visited the family member several times each day to facilitate UI care. Two of the care recipients also experienced advanced symptoms of dementia. Home care service duration for personal and nursing care ranged from one to four years ( $\bar{x} = 2.5$  years) and was provided by home health aides, registered nurses, case managers, and



physiotherapists. Participants represented the predominately Caucasian population of the geographic area.

### **Data Collection**

Each consenting participant's experience was explored in two tape-recorded in-depth semi-structured interviews lasting one to two hours in duration. A semi-structured interview guide was used to facilitate the family caregiver's sharing of his or her thoughts and experiences in the management of UI (Appendix C). The format of the interviews was flexible and evolved in response to the participants' uncovering of their experiences of UI KT. The interviewing process evolved through responsive sensitiveness to the directions and issues emanating from the interviewees. Following reflection and preliminary analysis of each initial interview, in each second interview, the researcher also responded sensitively to the issues and directions identified by the participant in the initial interview. Thus, the sequential interviews enabled more in-depth exploration of participants' experience of KT and greater clarity and accuracy of the mutually constructed interpretation. All interviews were audiotaped and transcribed verbatim.

### **Data Analysis**

Data contained within transcribed interviews and field notes were analyzed through an iterative process of immersion and crystallization (Lincoln & Guba, 1985). Analytic iterations were achieved by moving back and forth within the phenomenological data, constantly observing, articulating, and delving deeper into the narrative text to examine pre-existing meanings and to move to a deeper understanding through analysis, integration, and synthesis of the data into themes (Reason & Rowan, 1981; Van Manen, 1997). The researcher reflected on the meaning of the data by reading and re-reading the

interview transcripts while listening to the tape-recorded interviews to identify subtle nuances that could inform the interpretive analysis.

Initially, transcribed data were coded to identify categories and sub-categories which then were explored for relationships and themes (Appendix R). The researcher tentatively created themes, developed patterns of how data crossed themes and how the themes may have crossed interview participants, and then integrated thematic findings into a holistic interpretive analysis using Spiegelberg's (1982) analysis approach. The analysis steps included: investigating, intuiting, analyzing and describing the phenomenon, exploring the particulars or essences, watching for modes of appearing, exploring the constitution of the phenomenon in consciousness, suspending belief in its existence, and interpreting the meanings which are not immediately manifest (Spiegelberg, 1982). Peer review by dissertation supervisors assisted in promoting coherence and cogency of the findings, thus enhancing in-depth interpretation of the data (Whittemore, Chase, & Mandle, 2001).

### **Authenticity and Credibility**

Several strategies were used to promote the credibility (Lincoln & Guba, 1985) and authenticity (Sandelowski, 1986) of the phenomenological research findings. Authenticity was promoted through member checking during the interviews and again during preliminary interpretations of findings to determine whether the researcher's interpretation of the interview data made sense of the participant's experience (Whittemore et al., 2001). Credibility was facilitated through verbatim transcription of audio-taped interviews to ensure that the content of the data was accurate (Whittemore et al., 2001). Selection of an appropriate study design and methodology (Morse, 1991), data analysis methods of immersion and crystallization (Van Manen, 1997), mutual discovery

of the experience of participants through data collection and interpretation, extensive time allocation for the interview process, and peer review (Reason & Rowan, 1981) also promoted authenticity and credibility.

The researcher engaged in a process of reflexivity throughout the research process (Sandelowski, 1986; Todres & Wheeler; 2000), reflecting on what was happening in the study, her own assumptions, how and why these assumptions may have changed over the course of the study, how the text was being interpreted, how decisions were being made, her response to events during the study, and the nature of co-creation of study findings.

The researcher's insights and observations were recorded in memos and field notes as the analysis proceeded. Memos included critical reflections on emerging themes and conceptualizations associated with the data. Field notes fostered reflection on the data, potential interpretations of the data, decisions, approaches, changes, and rationale for choices throughout the data collection and analyses processes (Mulhall, 2003).

### **Ethics Approval**

Ethics approval was obtained from the Health Sciences Research Ethics Board of the University of Western Ontario ( University of Western Ontario Research Ethics Board, 2008) and the Behavioural Research Ethics Board at the University of Saskatchewan (University of Saskatchewan Research Ethics Board, 2008). The study participants were informed that they could refrain from answering any questions which felt uncomfortable, and/or withdraw from the study at any time without loss of access to or continuation of home care services. Participants also were informed that confidentiality and anonymity would be maintained for all data collected. All data stored on computers were password protected, and tape recordings, memory keys, and transcripts were maintained in a locked filing cabinet in the researcher's office.

## Study 2

### Statement of the Problem

Research suggests that family caregivers lack knowledge about in-home continence promotion for elderly care recipients. To date, research affords little insight into our understanding of how in-home paid care providers, family caregivers and home care recipients interact to create KT as it relates to the management of UI. Exploratory research is needed to enhance understanding of the process of in-home KT.

### Statement of Purpose

The aim of this study was to enhance understanding of the process of KT between and among paid care providers (such as professional nurses and unregulated care providers), unpaid family caregivers, and care recipients. Such knowledge might inform *how* UI management knowledge might be translated within in-home nursing practice and family caregiving. The research question posed was: ‘How do paid care providers, family caregivers and home care recipients enact UI KT within the context of in-home care? Ultimately, illumination of the process of KT may assist in: a) understanding caregivers’ experience of KT, b) development of substantive theory to advance understanding of how to go about the process of KT among paid providers, unpaid family caregivers, and care recipients, c) improved continence care management for the clinical and social problem of UI, d) development of broader KT strategies for application in family caregiver settings, and e) development of continence health promotion policy to support the prevention of associated UI costs and long term care admissions.

### Study Design

Grounded theory method aims to generate a theory that accounts for social interaction patterns that are enacted by participants, in this instance the social interaction

process of UI KT among paid providers, unpaid family caregivers, and home care recipients. Grounded theory illuminates the influences that social interactions and social contexts have on the behaviours that emerge from the perspective of those people being studied. Thus, grounded theory is appropriately suited to the investigation of social interaction focused on UI KT.

Symbolic interactionism, that is, reflection on the experience and meaning of interactions in social contexts that may change knowledge of social behavior and social engagement, provides the theoretical perspective for grounded theory research (Glaser & Strauss, 1967). Glaser (1978) emphasizes that data and theory emerge through the analysis of basic social processes without the use of preconceived theoretical frameworks and coding themes. Glaser's approach to grounded theory method afforded clear methods and techniques for constant comparative interpretive analysis of social interaction in process. This choice avoided the limitations of prescribed abstract theoretical procedures (Corbin & Strauss, 2008) or the lack of structured interpretive methods (Charmaz, 2009).

### **Recruitment and Sampling Strategy**

The sampling strategy is not pre-determined in grounded theory (Glaser, 2001). Access to family caregivers, care recipients and health care providers (e.g., nurses) was gained through established relationships with case managers, health care providers, and administrative staff within the home care department of the health region. As purposive and theoretical sampling were used for the sample selection, the number of participants was determined by the quality of the participants' experiences, their ability to reflect on and report their experiences, and the concepts and constructs that guided further theoretical sampling. A home care case manager assisted in the initial identification of in-

home client/caregiver dyads who were both involved in UI care and willing to be contacted by the researcher. Case managers selected and then contacted potential participant dyads which included home care clients over 65 years of age with continence management issues together with their informal caregivers from a database of home care service recipients and family caregivers. Home care health care case managers and providers (i.e. nurses) provided letters of information outlining the purpose of the study and expectations of the participants (Appendices D and E) and requested consent from each of the participants in the dyads approached to have their name and telephone number provided to the researcher. Home care office support staff placed an introductory letter (Appendix F) prepared by the researcher in the home care office mail boxes of all home care nurses and home health aides. Home care providers who consented to an office phone call from the researcher gave their signed letter of introduction (with the researcher's name on the front of a sealed envelope) to the home care support staff. The researcher obtained these signed letters from the support staff and then contacted the potential consenting participants, further explained the study, and sought formal informed consent for their participation (Appendices G, H, and I).

Sampling began by purposefully selecting out family caregiver, care recipient, and paid care provider triads from the sampling frame of family caregiver-client dyads who also had involvement of consenting providers to explore how KT unfolded. To build a grounded theory study of the social process of UI KT, theoretical sampling followed, engaging other participants with the potential to provide greater depth of data related to key concepts and constructs. The intent of theoretical sampling is to identify and refine categories of data through a process of constant comparative analysis throughout the data collection process (Glaser, 1978). Theoretical sampling was used to choose research

participants who might inform exceptions and further development of the emergent core concepts and categories within the data. Ultimately, 23 people representing these three groups of participants were engaged to inform the answer to the research question.

The ultimate sample size and composition were determined by the adequacy of data, that is, the extent to which the collected data saturated the categories and components of the grounded theory derived. Sampling ceased when ‘no new properties of categories’ emerged from comparisons of theoretical categories (Glaser, 1978). Purposive and theoretical sampling also promoted appropriateness of the sample selection to inform the answer to the research question. Glaser explains that theoretical sampling allows the researcher to explore the meaning of categories, ‘discover variation and context’ within them and between them, and identify gaps among categories and their dimensions. The researcher thus pursues a sample that appropriately informs the answer to the research questions.

### **Data Collection**

Audio-taped semi-structured interviews (Appendices J, K, and L) were undertaken to elicit data explaining what was going on, who was involved, how they were involved, how activities were organized, how the UI KT process unfolded, and what knowledge about UI was contributed by whom, when and where, and how. In addition, observations of interactions were documented in field notes if and as potentially relevant KT interactions transpired within the in-home context during the researcher’s data collection visits (Appendix M). All interviews were audiotaped and transcribed verbatim for analysis. Field notes explicating subtle nuances of the context in particular the researcher’s observations and questions related to the participants’ behaviors, intents,

needs, thoughts, understandings, expectations, social interactions and evidence of tacit knowledge were made during each visit.

### **Data Analysis**

The constant comparative method of analysis involves an ongoing process of theoretical sampling and memoing (Glaser, 1978). Substantive coding is the process of conceptualizing the empirical properties of the interview data. Substantive coding includes open coding, selective coding, and theoretical coding to identify, cluster, integrate, and delimit the categories created. Initially, the data were explored line-by-line through open coding to identify the properties of each unit of data. Next, units of data were compared across content within each interview, across interviews with each participant, and across interviews of all participants. The dimensions of core concepts and categories were generated by constantly comparing concepts and incidents to incidents (that is, indicators of a category or concept), and seeking the main theme or category revealed by the units of data (Glaser & Strauss, 1973). Selective coding was then used to identify the basic social process or core variable, to code variables that related to the core variable, and to undertake an ongoing comparison of incidents with the properties and dimensions of these variable categories and the core variable.

Theoretical coding involved examining relationships among categories (Glaser & Strauss, 1973). As theory emerged from the data, constant comparison was used to compare the data with the emergent theory to further define dimensions of categories and to see if the data supported the categories, core variable, and the relationships of the categories with the core variable. The researcher also searched for data that did not support the emergent concepts and theory. Possible exceptions to the theory, for example age- and gender-related specifics, were monitored by increasing diversity of the sample,



thereby expanding an understanding of the actual categories and dimensions and enabling refinement of an interpretation of the findings (Glaser & Strauss, 1973). Categories were theoretically saturated when no new dimensions of a category emerged through constant comparative methods. The researcher's perspectives on the meaning of the categories and their associated indicators or dimensions, and the relationships between and among the theoretical concepts and categories in the emergent theory were recorded in the form of memos. Examination of the literature also occurred during the analysis stage to inform the emerging theory.

### **Qualitative Rigor**

Glaser's (1978) criteria for judging the rigor of a grounded theory study, including fit, work, relevance, and modifiability, were used to enhance qualitative rigor. Fit relates to the extent to which the categories emerge from the data and represent the underlying data patterns and variation in the behaviors that comprise the basic social process of the grounded theory. Fit was continually refined and strengthened by constant comparisons during data analysis (Glaser).

Work is defined as the ability of the grounded theory to provide predictions of what occurs in the topic area through explanation of the relationship of categories. The criterion of 'work' also refers to how the relationship of the concepts accounts for the basic social process uncovered in the data. To promote the criterion of work, the participants' language was used as much as possible in developing the themes.

The criterion of relevance refers to the extent to which the theory, which is based on theoretical explanation of the relationships between and among categories, informs the key concerns of the respondents, rather than any pre-existing notions of theoretical constructs and relationships. Relevance of this grounded theory study was supported by

selection of participants according to their experiences with UI KT, thereby enhancing the applicability of the theory to the process of in-home UI KT. To support the criteria of work and relevance, participants had the opportunity to confirm the research findings during member checking processes.

The criterion of modifiability was achieved as new data emerged and the researcher modified emerging or established analyses as conditions changed (Glaser and Strauss, 1973). Participants had the opportunity to review the study findings, further inform the themes, and authenticate study findings through member checking. Guidance for modification of the transcribed and analyzed data also was provided by the student's dissertation committee. The theory ultimately described in this dissertation has the potential for modifiability in subsequent investigations when new relevant data are uncovered and compared to the existing units of data.

Continual reflection during the data collection and analysis phases of the study entailed the researcher asking her own questions about fit, workability, relevance and modifiability of emergent categories, thus generally supporting the criteria of qualitative rigor and concurrent analysis of the data. Auditability was addressed by maintaining raw data, field notes, and memos, providing an audit trail of the various steps taken throughout the research process. Memoing followed a process as described by Glaser (1978). Memoing encouraged critical reflection regarding the meaning and assumptions underpinning data and codes, as well as definition and linkage of the properties of categories identified to formulate the theory. Memoing also provided guidance for further coding and theoretical sampling, thereby enhancing the authenticity of the theory discovered through the research process.

## **Ethics Approval**

Ethics approval was obtained from the Health Science Research Ethics Board of the University of Western Ontario and the Behavioral Research Ethics Board at the University of Saskatchewan. In accordance with Health Information Privacy Legislation, all participants received a letter of information (Appendices D, E, and F) and letter of consent (Appendices G, H, and I) that was discussed as part of the process of recruiting and obtaining informed consent. The researcher was responsible for obtaining consent for this study, for any future potential secondary analysis of the participants' data, and for providing a copy of the consent to the individuals who were participants in the study. The participants were informed that they could refrain from answering any questions which caused them to feel uncomfortable and/or could withdraw from the study at any time without fear of jeopardizing their access to or continuation of services. The study participants were asked at the time of the interview if they wished a summary of the results of the study. This response was recorded on the consent form. If the participant wished to receive study results, an executive summary was mailed to the participant upon study completion.

Confidentiality was maintained by using code numbers in lieu of names on all study records and data. Coded transcripts were secured in locked filing cabinets in the researcher's office. All audio tapes will be erased and interview transcripts will be destroyed after seven years. The researcher displayed ethical conduct at all times in accordance with ethical accountability standards (Tri-council, 2005; University of Saskatchewan Research Ethics Board, 2008; University of Western Ontario Research Ethics Board, 2008).

### **Dissemination Plan**

For each of the two studies constituting this investigation, the researcher explored with the study participants how to proceed with communication of study results to home care providers, clients, and their caregivers. Future opportunities for the researcher and caregivers to play a facilitative role to promote consideration of the research findings for application within in-home KT also were explored. Dissemination of the results through publication in refereed periodicals and professional newsletters, and at gerontological, health promotion, home care, and KT conferences as well as educational sessions associated with health/social care organizations, academic settings, professional associations, policy makers, and decision makers, has begun.

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## CHAPTER FOUR

### FAMILY CAREGIVERS' EXPERIENCE OF IN-HOME KT

#### Introduction

Urinary incontinence (UI), defined as the unintentional excretion of urine (Abrams et al., 2003), is a principal cause of the collapse of informal in-home elder care arrangements and care recipient admission to long-term care (Farage, Miller, Berardesca, & Maibach, 2007; Thomas et al., 2004). Forty-six percent of elderly home care recipients experience symptoms of UI (Du Moulin, Hamers, Ambergen, Janssen, & Halfens, 2008) and this is anticipated to increase with an aging population (Canadian Continence Foundation, 2007). Urinary incontinence can be addressed through conservative treatment and continence promotion (Cheater, 2009; Fader, Bliss, Cottenden, Moore, & Norton, 2010). However, unpaid caregivers who provide personal, social and health care for 98% of older adult family members and friends receiving home care services (Canadian Institute for Healthcare Information [CIHI], 2010), may lack knowledge about continence promotion and management (Jansen & Forbes, 2006). Caregivers, herein referred to as family caregivers, have significant problems managing UI (Brittain & Shaw, 2007).

Yet within the in-home context, little is known about what knowledge family caregivers may have (Crooks, Williams, Stajduhar, Allan, & Cohen, 2007; Schumacher, Stewart, Archbold, Dodd & Dibble, 2000) or require to manage continence successfully (Shimanouchi, Kamei, & Hayashi, 2000) and thereby avoid these devastating problems. Furthermore, knowledge requirements may vary according to the values, expectations, and context of various individuals and groups (Bowen, Erickson, Martens, & Crockett, 2009; Davies, Nutley, & Walter, 2008; Dickinson, 2005) as well as with types of



knowledge, such as experiential and tacit ‘how to’ knowledge (Ferlie, 2005; Scott, Seidel, Bowen, & Gall, 2008), and research evidence (Lomas, 2005). Given these uncertainties about family caregivers’ experience of and involvement in the process of knowledge translation (KT), it is inadequately informed.

Knowledge translation is a process that includes the creation, exchange, enactment, and application of knowledge within an interactive context to promote health (Canadian Institutes of Health Research, 2009). The KT process is informed by pre-existing personal knowledge, experiential learning, and preferred sources of information, all often linked to social interaction (Nutley, Walter, & Davies, 2003).

To date, research has focused on professionals’ didactic teaching techniques to meet the KT needs of caregivers. Studies have not attended to the exploration of family caregivers’ experience of KT related to UI management. The limited UI research conducted at the in-home individual practice level has focused on: a) family caregivers’ experience of providing UI care (Cassells & Watt, 2003; Gallagher & Pierce, 2002; Upton & Reed, 2005), b) interventions with UI clinical practice guidelines (CPGs) such as assessment and bladder training protocols that can support effective and conservative UI management (Newman, 2009; Ostaszkiwicz, Chestney, & Roe, 2010; Roe & Moore, 2004), and c) the explicit content of caregivers’ knowledge about health conditions and clinical guidelines (Colling, Owen, McCreedy, & Newman, 2003; Schumacher et al., 2000).

We have limited knowledge of family caregivers’ experience of KT, specifically for UI management between and among in-home care professionals, personal care workers and unpaid family caregivers, and those receiving UI care. Not only are both client and family caregiver health ultimately undermined by the strain of unsuccessful UI

management (Cassells & Watt, 2003; Raiwet & Phillips, 2001), but also UI results in annualized expenditures for families of \$2.6 billion in Canada (Canadian Continence Foundation, 2007) and \$14.2 billion in the United States (Hu et al., 2004). Exploratory research is needed to enhance understanding of family caregivers' experience of UI KT in the home care context.

### **Statement of Purpose**

The aim of this initial study was to explore family caregivers' KT experience related to the management of continence in elderly care recipients. The research question was: 'What is family caregivers' experience of UI knowledge translation?

### **Literature Review**

A literature search using the terms of in-home knowledge translation, community nursing care, caregivers, social interactions, and urinary continence, was conducted of the online databases of CINAHL, Medline, Embase, Social Work, ERIC, Psych Info and the Cochrane Library. Nine published research studies were selected as providing insights to inform family caregiver KT and the gaps associated with caregiver KT of in-home UI promotion and management techniques. No studies were found that explored family caregivers' experience of KT specifically for continence promotion and management.

Research to date has explicated paid care providers' and family caregivers' role enactment within a social interaction context relevant to KT for in-home elder care. A qualitative descriptive (Benzein, Johansson, & Saveman, 2004), multi-case (Guberman, Lavoie, Pepin, Lauzon, & Motejo, 2006), and critical ethnographic (Ward-Griffin, 2001) study revealed that nurses perceive their role as that of the expert provider with expectations that family caregivers would provide care and receive prescriptive task-focused education to enable elder care. While these findings suggest that paid providers'

perceptions of caregivers may be a factor in family caregivers' experience of KT, these three studies did not illuminate family caregivers' perspectives on role enactment relevant to in-home education or KT.

Conversely, two qualitative studies (Heinrich, Neufeld, & Harrison, 2003; Sims-Gould and Martin-Matthews, 2010) found that family caregivers assumed the roles of in-home paid providers instructing and collaborating with providers to provide elder care. However, these studies did not elaborate on family caregivers' experience of KT that may have transpired between the caregivers and the paid care providers.

These studies of role enactment relevant to KT for in-home elder care suggest that both professionals' task-related instruction and expectations of family caregivers' involvement may be factors in caregivers' experience of KT. Findings also reveal that family caregivers ascribe the same role expectations to themselves, although describing more proactive collaborative roles with providers.

Research to date also has described family caregivers' experiences and expectations of KT. In an ethno-nursing study, Van den Brink (2003) found that family caregivers may refuse to use assistive devices if home care education is provided in a prescriptive, didactic way that is not congruent with the family's desire to work and learn through collaboration with paid providers. Findings from a descriptive exploratory sub-study (Schumacher et al., 2002) suggest that family caregivers experienced ongoing care management education and problem-solving with professional providers as a necessary part of learning about in-home care. However, family caregivers perceived that the one-time provision of didactic teaching was not effective. These studies illuminate the KT expectations and challenges that family caregivers experienced in relation to chronic in-

home care, but have not addressed family caregivers' experiences with in-home professional teaching and KT for UI management.

In a qualitative observational sub-study of family caregiver-care recipient (n=42 care recipients/caregiver dyads) interactions during bathing care researchers (Mahoney, Trudeau, Penyack, & MacLeod, 2006) found that a) direct observation of family caregiver and care recipient interactions during bath time can enhance the paid providers' knowledge of the caregivers' and care recipients' bathing experience, b) paid provider and family caregiver knowledge-sharing can occur to co-create an approach to the bathing process, and c) receipt and enactment of care information by the family caregiver may be affected by hearing loss, discomfort associated with providing personal care to a parent, and a previous negative or positive bathing experience. In addition, family caregiver practice sessions may enhance in-home evidence application. While findings suggest a few strategies and issues relevant to KT, questions about KT, particularly KT relevant to UI management, have not been investigated.

Findings from a quasi-experimental intervention study (Colling et al., 2003), which focused on professional teaching and family caregiver coaching to manage in-home bladder training, demonstrated significant improvement of client-relative UI symptoms and UI care, suggesting that the KT approaches were effective. However, these family caregivers were not always able to follow the instructions provided due to other physical and psychological demands of caregiving. This investigation focused on the knowledge transfer and knowledge-sharing actions of only the care providers. No description was provided of the specific educational approaches used by the nurses or the family caregivers' KT experience. Further family caregiver consultation was recommended to inform approaches to in-home UI KT.

Overall, the majority of family caregiver KT research has been limited to the study of the transfer of paid care providers' elder care knowledge to in-home caregivers. If we are to increase understanding of family caregivers' perspective of KT to optimize approaches for UI in-home management, further in-depth phenomenological investigation is needed.

### **Methodology and Methods**

A hermeneutic as opposed to a transcendental descriptive phenomenological approach (McWilliam, 2010) was used to investigate caregivers' experience of UI KT. Hermeneutics has as its aim the interpretation of phenomena to uncover hidden meaning (Mackey, 2005; Schwandt, 2000). The hermeneutic phenomenological approach is premised on the belief that phenomenological understanding is intersubjectively constructed. Hence, the researcher's presence and participation shapes the lived experience that is being investigated (Golomb, 2002; McWilliam; 2010; Raynova 2002). As it is ontological rather than epistemological in its orientation (Van Manen, 1997), the hermeneutic phenomenological approach is congruent with the study of contextualized data about the human experience of KT and the intersubjective nature of knowledge as co-constructed by the researcher and participant (Lopez & Willis, 2004). As well, hermeneutic research is premised on assumptions that the world is dynamic and constantly changing, facts and values are intertwined, and knowledge is historical and situated in context. Phenomenology is not guided by a priori theory, as it is based on the premise of discovering and understanding a phenomenon, often phenomena about which there is little published literature. These attributes render hermeneutic research particularly well suited to the investigation of KT through social interaction.

## Study Context

This investigation was conducted within a south central rural home care setting of one of the 12 health regions in Saskatchewan, namely the Health Authority Board that is accountable for the health services provided to the 56,000 residents of this region. The health authority receives a global funding envelope for allocation across all hospital, long-term institutional and continuing care services, administering these resources within the parameters of three different collective agreements for home care service staff. Home care, a sub-service of continuing care, is provided to 2,500 clients through an integrated single point of access model for team-based continuing care services. Home care services include: needs assessment and care coordination, home nursing, home health aide services, volunteer services, physiotherapy, occupational therapy, palliative care, respite, intravenous therapy, and Meals on Wheels. Home care team members (nurses, physiotherapists, home health aides, social workers, case managers, and occasionally, physicians) are represented on regional and provincial care, human resource, financial, and information management quality improvement teams to facilitate evidence-based care and service.

The health region is committed to the inclusion of family caregivers and care recipients in team-based quality improvement initiatives to increase the quality of life of those who experience UI, and ultimately, to the reduction of long-term care admissions and the costs associated with UI management. Approximately 70% of those receiving home care services in the health region experience symptoms of UI. Thus, the health authority that comprised the context of this investigation was committed to working with the researcher to explore KT related to the provision of in-home UI care for an older adult.

## Recruitment and Sampling Strategy

From a database of home care service recipients and family caregivers in the selected region, case managers and/or home care nurses identified and approached English-speaking family caregivers providing in-home UI care to older family members, providing letters of information about the study (Appendix A), and requesting consent to provide their name and telephone number to the researcher. The researcher then contacted the family caregivers, further explained the study, and requested formal informed consent for participation (Appendix B).

Purposive sampling (Patton, 2002) was undertaken to select family caregivers with varied educational backgrounds, age, gender, experience with UI care, and problems with UI management. The appropriateness of data was thereby promoted (Morse, 1991) for capturing the experience of KT for the diversity of in-home caregivers who provide UI care to elderly care recipients. The richness of the data obtained through the phenomenological approach allowed for small numbers of informants (MacDougall & Fudge, 2001). Recruitment and sampling of participants ceased when theme saturation was achieved, that is, when no new information on family caregivers' experience of UI KT was uncovered, and insights and understandings adequately answered the research question (Morse).

Four family caregivers (three females, one male) participated in the study. These caregivers were the spouses and adult children of the home care recipient, ranged from 60 to 90 years in age ( $\bar{x} = 76$  years), and cared for home care recipients experiencing symptoms of UI. Two of the care recipients also experienced advanced symptoms of dementia. Home care service duration for personal and nursing care ranged from one to four years ( $\bar{x} = 2.5$  years) and was provided by home health aides, registered nurses, case

managers, and physiotherapists. Participants represented the predominately Caucasian population of the geographic area.

### **Data Collection**

Each consenting participant's experience was explored in two tape-recorded in-depth semi-structured interviews lasting one to two hours in duration. A semi-structured interview guide was used to facilitate the family caregiver's sharing of his or her thoughts and experiences in the management of UI (Appendix C). The format of the interviews was flexible and evolved in response to the participants' uncovering of their experiences of UI KT. The interviewing process evolved through responsive sensitiveness to the directions and issues emanating from the interviewees. Following reflection and preliminary analysis of each initial interview, in each second interview, the researcher also responded sensitively to the issues and directions identified by the participant in the initial interview. Thus, the sequential interviews enabled more in-depth exploration of participants' experience of KT and greater clarity and accuracy of the mutually constructed interpretation. All interviews were audiotaped and transcribed verbatim.

### **Data Analysis**

Data contained within in transcribed interviews and field notes were analyzed through an iterative process of immersion and crystallization (Lincoln & Guba, 1985). Analytic iterations were achieved by moving back and forth within the phenomenological data, constantly observing, articulating, and delving deeper into the narrative text to examine pre-existing meanings and to move to a deeper understanding through analysis, integration, and synthesis of the data into themes (Reason & Rowan, 1981; Van Manen, 1997). The researcher reflected on the meaning of the data by reading and re-reading the



interview transcripts while listening to the tape-recorded interviews to identify subtle nuances that could inform the interpretive analysis.

Initially, transcribed data were coded to identify categories and sub-categories which then were explored for relationships and themes (Appendix R). The researcher tentatively created themes, developed patterns of how data crossed themes and how the themes may have crossed interview participants, and then integrated thematic findings into a holistic interpretive analysis using Spiegelberg's (1982) analysis approach. The analysis steps included: investigating, intuiting, analyzing and describing the phenomenon, exploring the particulars or essences, watching for modes of appearing, exploring the constitution of the phenomenon in consciousness, suspending belief in its existence, and interpreting the meanings which are not immediately manifest (Spiegelberg, 1982). Peer review by dissertation supervisors assisted in promoting coherence and cogency of the findings, thus enhancing in-depth interpretation of the data (Whittemore, Chase, & Mandle, 2001).

Authenticity was promoted through member checking during the interviews and again during preliminary interpretations of findings to determine whether the researcher's interpretation of the interview data made sense of the participant's experience (Whittemore et al., 2001). Mutual discovery of the experience of participants through data collection and interpretation, extensive time allocation for the interview process, and peer review (Reason & Rowan, 1981) also promoted authenticity and credibility.

### **Ethics Approval**

Ethics approval was obtained from the Health Sciences Research Ethics Board of the University of Western Ontario and the Behavioural Research Ethics Board at the University of Saskatchewan. The study participants were informed that they could refrain

from answering any questions which felt uncomfortable, and/or withdraw from the study at any time without loss of access to or continuation of home care services. Participants also were informed that confidentiality and anonymity would be maintained for all data collected. All data stored on computers were password protected, and tape recordings, memory keys, and transcripts were maintained in a locked filing cabinet in the researcher's office.

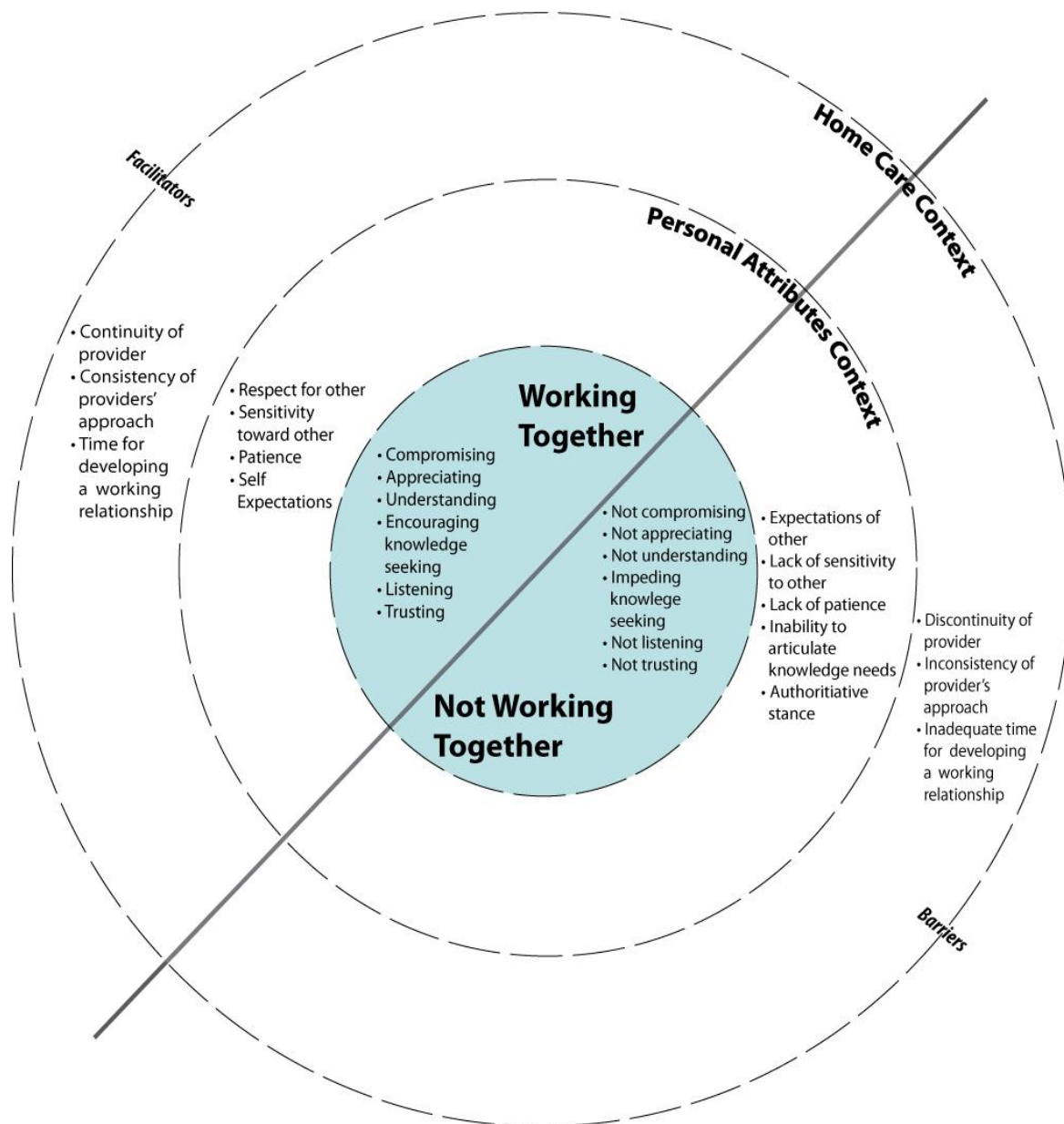
### **Findings: Working Together/Not Working Together**

Family caregivers experienced KT as a holistic and ongoing dynamic relational process of working together and not working together (Figure 4.1). This experience was constantly changing within six dialectical sub-themes: *compromising/not compromising, appreciating/not appreciating, understanding/not understanding, encouraging knowledge seeking/impeding knowledge seeking, listening/not listening, and trusting/not trusting*. These dialectical patterns of 'working together/not working together' are presented in the following sub-sections.

#### **Compromising/Not Compromising**

Family caregivers perceived that compromising was an important element of paid providers' and care recipients' communication of ideas about UI care. One caregiver stated:

We [caregivers] ... compromise – it is not always our ideas that we ... [implement] .... We [caregivers] should always be open to change to someone else's [care provider or care recipient] idea [about how to manage UI care] .... We need to listen and be open to the ideas of others.



*Figure 4.1* Family Caregivers' Experience of Knowledge Translation:  
Working Together/Not Working Together

However, family caregivers perceived that paid care providers were not always willing to compromise regarding their approaches to UI care. One family caregiver described her frustration when attempting to share her care plan knowledge with

providers, who would not seem to consider her perspective on how to promote consistent application of the care plan. Ultimately, KT was impeded when paid care providers would not change their individual procedures and thus, did not work with the family caregiver in a way that promoted KT:

I [caregiver] said ... “I would teach everyone [home care providers] how to do [care techniques].” It was ... frustrating to me that everyone had their own way of doing [and persisted despite teaching efforts] .... Therefore, I just backed off, so we were not ... working together.

### **Appreciating/Not Appreciating**

Family caregivers also perceived that conveying appreciation for others’ care contributions supported relationship development, and in turn, KT. One family caregiver eloquently shared an insight into KT experienced in a relational exchange of appreciation for the paid care provider’s and family caregiver’s in-home care efforts:

It’s not about coming into my house to please me. It’s like a mirror ... I [caregiver] know you appreciate what I do as a caregiver, and I appreciate you as the care provider ... It mirrors back and it is like an exchange. You go away and I go away, and everyone is happy – I feel good about myself and you feel good about yourself because you helped me to learn. You are doing your job.

Conversely, not conveying appreciation for each other’s efforts meant that the experience was not one of KT. One family caregiver reported that she found it difficult to learn when the paid providers did not appreciate her contributions to in-home care: “It was hard to follow what they [providers] were trying to teach me ....They did not appreciate that I knew what worked.”

### **Understanding/Not Understanding**

In addition to ‘appreciating’ family caregivers’ in-home care knowledge, family caregivers perceived that understanding was a part of their experience of KT: “It is important they [providers] have some understanding of what [care techniques] work.” One particular caregiver also illuminated how understanding the other’s perspective was essential to KT:

Understand [the other’s perspective] – then you [caregiver/care recipient dyad and care provider] can talk and do anything together. You [caregiver/care provider] can get so you don’t have to talk to each other – you just know what the other person would do. It becomes automatic.

When family caregivers perceived that paid providers did not understand, they described experiencing failure to achieve KT: “I [caregiver] don’t think they [providers] really understood how his [care recipient] condition ... had deteriorated over the past few weeks ... and what help and information I needed ... and how I needed this help and information [for in-home care].”

### **Encouraging Knowledge Seeking/Impeding Knowledge Seeking**

Part of family caregivers’ experience of KT was described as encouraging or impeding knowledge seeking. One participant explained:

I’d asked them [providers] questions about what we [caregiver and care recipient] should do and ... “Yes, that’s what you do [care provider’s response].” One gal [care provider] said, “Anytime you have a problem just phone me.” .... I gave her my cell phone, and she would always call me if something came up [regarding learning about home care and/or UI care].

Conversely, participants also experienced paid providers impeding knowledge seeking by not affording them the opportunity to ask questions. As one family caregiver explained: “They [care providers] look ... over you [caregiver] when you ask a question ... They weren’t paying any attention to me.” Another family caregiver perceived that her knowledge contributions were not welcomed by the paid care provider and, therefore, felt unable to engage in knowledge-seeking for KT:

... I [caregiver] always felt that they [doctors] don’t give people credit at all [don’t acknowledge caregiver’s knowledge].... One doctor said to me, “How do you know he [care recipient] has blank spells?” I said, “I don’t. I’m just telling you that he wasn’t there; he was absolutely blank.” He didn’t believe a word I was saying .... So, I stopped saying anything or asking questions.

### **Listening/Not Listening**

Listening was deemed by family caregivers to be part of their KT. One caregiver commented:

... [Providers should] allow the person involved [care recipient] to be listened to and have some say in how things are done [UI care].... If you [providers] try to tune into what I am trying to communicate to you, it helps ... [ie. KT about the care recipient’s UI care needs] to work together.

Conversely, family caregivers perceived that if paid care providers did not listen to the caregiver’s knowledge, KT did not readily transpire. One caregiver said: “So many people could be a lot more help if they [home care providers] would just listen [to the caregiver], and they don’t. It’s like they think I don’t know anything because I don’t have an education.”

### Trusting/Not Trusting

Family caregivers felt that trust and a sense of comfort were also essential elements of the experience of KT. One family caregiver described learning about care innovations through providers whom she came to know and trust:

I learn from the people [providers] whose hearts are in it. They care and are always coming up with something new to do. They [care providers] care about how you are feeling. It's kind of nice when someone comes into your home and cares enough .... You know and you can trust them.

Family caregivers' not trusting paid care providers undermined their confidence in the paid care providers' potential for knowledge that caregivers might access from them. One caregiver described her experience of not trusting as follows:

It gives you [caregiver] a bad feeling when ... different ones [care providers] come in the door. You don't know them and wonder ... if you can trust the answers they might give to your questions [regarding care recipient's care].

Viewed holistically, findings revealed six dialectical patterns of relating that constituted the experience of KT. These patterns unfolded within social interaction processes that family caregivers experienced at one and the same time as *working together/not working together*. At times, compromising, appreciating, understanding, encouraging knowledge seeking, listening and/or trusting created an experience of KT encapsulated within 'working together' as stated by one caregiver, "understand the other's perspective and then you can do anything together". At other times, not compromising, not appreciating, not understanding, impeding knowledge seeking, not listening and not trusting led participants to conclude that "we were not working together" as noted by another caregiver, "some of them [providers] don't appreciate what

we [caregivers] know so we can't work together". In this instance, family caregivers described not experiencing KT.

### **Facilitators and Barriers of Working Together/Not Working Together: The Home Care Context**

Within the home care system, family caregivers perceived the following as contextual facilitators and barriers of KT: *continuity/discontinuity of care provider, consistency/lack of consistency in care provider approach, and time/inadequate time for developing working relationships.*

#### **Continuity/Discontinuity of Care Provider**

Continuity in the scheduling of the same paid care provider for in-home care was viewed by family caregivers as a facilitator of KT. Care providers who were assigned to work with the same family caregiver and care recipient over time became familiar with the in-home UI concerns and shared consistent UI management approaches. One family caregiver explained:

You [care provider] have to be the same person to be familiar with the situation [caregiver's and care recipient's UI concerns] and what you are talking about [UI management/care] ... Keep the same person involved until you get somewhere [with learning about UI] ... I wanted to meet with the same person as well so that when we were with grandma, each of us [care provider, caregiver, and care recipient] knew what each other knew [about the care recipient's UI care and education issues].

Continuity of the paid care provider assignment was highly valued as it afforded opportunities for the family caregiver to work with in-home providers and learn about techniques required for UI management. One family caregiver explained how she gained



knowledge from the paid care provider's demonstration of transfer techniques: "There was one gentleman ... who came in twice a week. He could work with me to show me how to move my husband [care recipient] so that I could wash him [provide UI care]."

Conversely, family caregivers felt that lack of continuity in assignments necessitated re-starting a working relationship with each new paid provider, ultimately impeding KT:

It would have been devastating to start [working and relating with a different care provider] all over again. All that mattered to us [caregiver and care recipient] were the people [care providers] who were looking after him and showing me what to do [to assist with UI care].

Family caregivers felt that the paid providers new to their home should be familiar with care responsibilities documented in the client's care plan but reported that such was not the case. Moreover, family caregivers were asked for care instructions, which often were unknown to the paid providers. One participant observed:

If they [home care agency] send somebody different to do something [in-home care], they [providers] should know what they are doing .... They would come in and say 'my name is such and such', and right away ask me what they [provider] were supposed to do .... 'How was I to know what they were supposed to do?' It would have been easier to do it [in-home care] myself .... I do realize that home care cannot always send the same people [providers], but there must be something we can do [to provide more continuity].

### **Consistency/Inconsistency in Care Approach**

Family caregivers perceived that KT was facilitated by consistent approaches to care. The ability of the family caregiver and paid provider to consistently relate and

communicate with an older family member promoted learning about UI care issues, as stated by one family caregiver: “If you [caregiver and care provider] are dealing and relating with an older person, don’t change anything. Be consistent with what you are doing [with learning about in-home UI care].”

One family caregiver commented on the frustration experienced in attempting to learn about UI care within the context of inconsistent approaches: “One care provider wanted to do it this way and one wanted to do it that way [bedsore and UI care]. We were having all kinds of trouble [with learning how to provide care].”

In summary, consistent approaches to care, most often afforded by continuity of paid providers, were experienced as a contextual facilitator of KT. Inconsistent care approaches underpinned by discontinuity of paid provider assignments were viewed as a contextual barrier to KT.

### **Time /Inadequate Time for Developing Working Relationships**

Family caregivers felt that working with paid care providers and care recipients over time was necessary to learn about UI and in-home care. As part of learning together, family caregivers also perceived that time enabled them to reflect on and understand different perspectives associated with UI teaching and learning approaches. As one family caregiver articulated:

As you [caregiver] work it through [learn in-home and UI care], you ease over time into what needs to be done and how you go about it .... Time is important to consider what has to be done [learning how and learning what has to be done]. If you [caregiver] don’t agree right away [with the UI learning and teaching approach] ... just think about it and come back to it after some thought.

When paid providers and family caregivers had little time together, family caregivers perceived their development of trust in the paid provider's ability to apply knowledge about the client and ultimately, KT, to be impeded. Conversely, trust, perceived as a component of relating to and caring for the other, evolved as the paid care provider spent time with the family caregiver and care recipient. During this time, family caregivers observed whether or not the paid care providers applied knowledge of the care recipient's needs to client care. One family caregiver shared the following experience:

If they [care providers] are coming in and in a rush, then we [caregivers] can't trust them [care providers' knowledge about care recipient's needs]. So you want to take the time so I [caregiver] can trust you [to apply client knowledge to in-home care].

In summary, family caregivers identified that their experience of KT within this home care context included both facilitators and barriers. Provider continuity facilitated KT as it permitted working together over time. Continuity of in-home assignments promoted paid provider familiarity with home care clients' UI concerns and enhanced consistency in UI management approaches, thereby facilitating KT. Family caregivers mistrusted paid providers who spent inadequate time with care recipients, perceiving that this meant inadequate knowledge of the care recipients and impeded in-home application of such knowledge.

### **Contextual Facilitators and Barriers of Working Together/Not Working Together**

**Personal attributes.** Personal attributes of both paid care providers and family caregivers themselves also constituted perceived facilitators or impediments to working together/not working together. Participants identified: *respect toward the other, expectations of the other, sensitivity toward one another, self-expectations for KT,*

*inability to communicate knowledge needs, patience with other, and authoritative stance.*

The following sub-sections present these personal barriers and/or facilitators of KT.

***Respect for the other.*** Family caregivers felt that respect toward the other was foundational to KT. In particular, participants conveyed that learning how to work respectfully with the client's experience of symptoms facilitated KT. Applying knowledge respectfully fostered the ability of the care recipient to respond to and connect with the paid care provider, and ultimately, this then facilitated working together to address care needs. One family caregiver who cared for a spouse with UI said:

I [caregiver] feel that they [providers] have to learn ... how to be kind and respectful to ... them [care recipients]. This is the way they have to be if they want to get a response from them [care recipients]. If they can't get a response from them, they [provider and care recipient] will not be able to connect and work together.

***Expectations of the other.*** Family caregivers expressed concern about caregivers' and paid care providers' expectations of one another having the potential to impede KT. As one family caregiver explained:

I [caregiver] am expecting them [providers] to be a certain way because they are home care providers. They are expecting me to be a certain way.... So we all have these expectations [for in-home care roles]. It's like we have a whole list of things to expect when we go into a home. We need to shut off this list of expectations; we need to be more basic [i.e. attend to how we relate to each other].

***Sensitivity toward one another.*** Family caregivers described how sensitivity could facilitate KT and lack thereof, impede KT. As one family caregiver commented:

“We [caregiver and provider] need to be sensitive to each other's need to learn ... and

how we are with one another.” Another described the paid provider’s insensitivity as a barrier to working together in KT: “It was hard to learn from them [providers] because some of them ... just sort of did the job [demonstrating UI care to caregiver] without feeling [any sensitivity] for his [care recipient] needs.”

***Patience with each other.*** Family caregivers also perceived that care providers’ role modeling of patience facilitated learning ‘how to be’ with others in a relational context, and hence, facilitated KT. One family caregiver explained how a paid care provider enhanced her confidence in her ability to work with a care recipient: “It was the patience they had and taught me – just keep at it and it will eventually happen [caregiver will enact ‘patience’ when working with care recipient].”

However, limited patience was experienced as a barrier to KT. For example, one family caregiver described how she developed and applied what she had learned:

I [caregiver] am learning more from those [care providers] who understand the ‘baggage’ [emotions associated with working with providers] and the way I react to them [that is, angrily when I don’t agree with them] than from the providers who react [reciprocate anger] to me.... The ones who are patient ... They help me realize that, I have to stop being like that ... I need to get a grip and count to 10 [to work with others].

One family caregiver recounted the lack of patience that she experienced with a new paid care provider who, lacking experiential care knowledge, sought knowledge from the client, who had dementia. The family caregiver’s lack of patience impeded KT from caregiver to paid care provider:

At the end just before he [care recipient] went into long-term care, my patience was really thin. When a new person [care provider] came in, I just didn’t have the

patience ... to share all of his [care recipient's] care information. She asked him dozens of questions. She was taking lots of notes ... But he hadn't answered one of those questions correctly.

***Self-expectations for KT.*** Family caregivers also described expectations they had for their own proactive role in KT, specifically in teaching paid providers about the care recipient's needs:

My job as a caregiver is to ensure that her [care recipient] needs are met and that she is comfortable ... If they [providers] don't do things so that she is comfortable, I can't just walk away and say to mom, "That's the way it is!" I have to learn how to say it better [communicate to providers how care is to be carried out] so that we can work with them.

***Inability to articulate knowledge needs.*** Family caregivers' perceived inability to articulate knowledge needs coupled with paid care providers' inability to understand caregivers' knowledge requirements was experienced as a KT barrier:

Most of the time, I almost never said anything; I don't know how. I just knew that they [care providers] looked at me as if to say, 'Oh, what do you want to know?' I didn't know what I wanted to know. I just wanted some help, and if I had known what I wanted, then I could have gone and done it. I felt like they [care providers] didn't understand [what I needed to know] ... I [caregiver] mean, it was my fault too, because I didn't know how to tell them [care providers].

***Authoritative stance.*** Family caregivers perceived an impediment in care providers' authoritative stance, conveyed when their inquiries about care information were not welcomed or their knowledge to inform approaches to in-home care. One family caregiver commented:

I think it would be helpful if they [care providers] were listening to me without making me feel that ... they were the boss sort of thing and that I was to listen to what they were saying and don't ask questions. That's the way I felt.

In summary, family caregivers' experience of KT revealed personal attributes that constituted facilitators and barriers of KT through the social interaction of working together/not working together. When personal attributes enabled the paid care provider and family caregiver to work together, KT was facilitated. However, when personal attributes created barriers to working together, KT was impeded.

### Discussion

In this study, family caregivers' experience of KT transpired through social interactions, particularly within working relationships, that were either facilitated or impeded by the context of home care and by the personal attributes of the participants themselves (Figure 4.1). The social interaction of working together/not working together was characterized by: *compromising/not compromising, appreciating/not appreciating, understanding/not understanding, encouraging knowledge seeking/impeding knowledge seeking, listening/not listening, and trusting/not trusting* all of which constituted the experience of KT. Continuity of the paid providers of home care, consistency of care approaches, and adequate time to develop working relationships as well as many personal attributes all contextualized working together/not working together, thereby entering into family caregivers' experience of KT.

Many of the social interaction components of working together/not working together uncovered in this study have been observed in previous research. Compromising approaches to care and listening have been identified in research that explored family caregivers' educational experiences and knowledge-seeking for in-home chronic care

(Jeon, 2004; Paun, Farran, Perraud, & Loukissa, 2004; Stoltz, Lindholm, Uden, & Willman, 2006). Others (Mahoney et al., 2006) have suggested that paid providers' acknowledgement of the emotional and physical decline of the care recipient, and recognition of caregivers' burden of care were part of family caregivers' experience of 'trusting of the provider' and ultimately, their experience of in-home KT. Kellet and Mannion (1999) also have described processes of 'appreciating and understanding' family caregivers' knowledge within family caregiver and paid care provider relationships. The findings of this study therefore are congruent with those of several other studies and further illuminate family caregivers' relational experiences of KT, in particular, UI KT, a previously unexplored topic.

The findings of this study suggest that power differentials constituted by paid care providers' knowledge bases create relational knowledge boundaries between family caregivers and home care providers. Knowledge is considered to be a form of power (Denis, Hebert, Langley, Lozeau, & Trottier, 2002). As well, social structures such as home care agencies, create power relations within in-home social interactions, which in turn, through their enactment (Giddens, 1991), also dynamically shape the social structure of which they are a part. Within the context of formalized in-home care, family caregivers' naturally experience the structure of relational knowledge boundaries and the agency of relational knowledge, hence power, in paid providers' didactic expert-driven teaching methods and failure to listen to family caregivers' perspectives on care approaches. Such experiences have been substantiated in previous research (Van den Brink, 2003; Ward-Griffin 2001). In addition, didactic educational interactions with family caregivers have been linked with caregivers' mistrust of paid providers (Jeon, 2004; Neufeld, Harrison, Stewart, & Hughes, 2008), providers' limited understanding of



in-home family caregivers' ways of learning (Heinrich et al., 2003; Van den Brink), and, ultimately, with family caregivers' perceived inability to engage in knowledge-seeking. As family caregivers' experience of relational knowledge boundaries previously has not been explored in the literature in a comprehensive way, these insights add to the knowledge in this field.

The dialectical patterns of family caregivers' experience of KT, as uncovered in this investigation, afford several insights into caregivers' social construction of knowledge. Family caregivers experienced the integration of tacit 'how to', experiential, and relational knowledge within social interaction regarding UI KT. These findings are similar to providers' experience of the social construction of knowledge observed in an investigation of knowledge translation about paid care providers within another home care context (McWilliam et al., 2009). The social construction of knowledge also has been examined from a theoretical perspective of social interaction within the context of professional organizations (Estabrooks, Midodzi, Cummings, Wallin, & Adewale, 2007; Jordan et al., 2009), nurses' 'relational inquiry' with patients (Hartrick-Doane & Varcoe, 2008), and overviews of the principles of adult learning for practice (Donaldson, Rutledge, & Pravikoff, 1999). However, to date, little attention has been given to how social interaction and adult learning perspectives might inform understanding of the knowledge family caregivers require and use in working together with paid care providers to manage UI. Thus, the insights gained in this study about family caregivers' social construction of knowledge may illuminate the refinement of UI KT approaches for family caregivers.

The findings of this study illuminate contextual and personal attributes that contribute to family caregivers' experience of KT during the process of formal provision

of in-home services. Several family caregiver and paid provider relational attributes, such as respect and sensitivity, parallel those found in the theoretical and research literature regarding interpersonal and therapeutic relationships (Forchuk & Reynolds, 2001; Peplau, 1997; Welch, 2005). Additional attributes described by family caregiver participants included their own inability to articulate knowledge needs and paid providers' inability to convey respect to informal family caregivers throughout the process of achieving KT. These particular findings illuminate the relevance of personal attributes to family caregivers' experience of KT.

The relevance of continuity in provider assignments to the building of provider-caregiver relationships, and in turn, the experience of KT was particularly apparent. This too, is congruent with the findings of previous researchers, who have revealed the need for paid in-home providers to have more in-home paid provider time and continuity for relationship development (Gantert, McWilliam, & Ward-Griffin, 2009). Peplau (1997) also asserted that continuity of interpersonal interactions and relationships constitutes much of the practice of nursing, wherein nurses apply knowledge of clients through connecting with them to understand and assist with problem solving to address their health challenges. Knowledge translation to promote optimal care is such a challenge.

Other studies have found that lack of client familiarity with the paid provider due to discontinuity of provider assignment (Woodward, Abelson, Tedford, & Hutchinson, 2004) contributes to the inability of family caregivers to transfer client care information to paid providers, particularly for those clients with complex chronic care conditions (Jansen et al., 2009; Sims-Gould & Martin-Matthews, 2010). Limited continuity in paid provider assignment also has been linked to the absence of educational guidance to meet family caregivers' needs for knowledge enabling them to manage in-home elder care

(Forbes et al., 2008; Forbes & Neufeld, 2008). In the Woodward et al. (2004) study, new providers who did not have an ‘accumulated’ knowledge, that is, knowledge developed over time about the home care recipient’s care needs and how to relate to the client, were unable to meet care requirements and to foster the client’s trust. Adding to this previous research, this study has provided additional in-depth insights into the contextual components of home care specifically related to family caregivers’ experience of working together to achieve UI KT, and added to the theoretical foundation of KT, specifically illuminating the nature of context identified in the PARiHS Theory to be a critical component of KT (Rycroft-Malone et al., 2002).

Consistent with the individualistic and intersubjective nature of interpretive research, these study findings cannot be generalized. In addition, the findings of this study may have been limited by the researcher’s ability to interpret participant data and the ability of the participants to articulate their experience of KT. Nevertheless, the findings of this study illuminate family caregivers’ experience of KT of practical ‘how to’ knowledge, particularly revealing the bidirectionality and relational nature of KT between paid care providers and family caregivers involved in in-home-care. As well, the findings add particulars that inform the PARiHS (Rycroft-Malone et al., 2002) and invite consideration of Structuration Theory (Giddens, 1991) to build the theory of KT.

### **Implications**

Health care providers may promote in-home KT through attention to the insights gained from this study. Provider enactment of relational social interaction processes such as listening to and appreciating family caregivers’ elder care knowledge may enhance their own and family caregivers’ learning about UI care. Doing so may foster family

caregivers' social construction of in-home tacit care knowledge and participation in mutually constructed solutions in KT efforts to enhance in-home UI care.

The findings from this study also provide insights into the design of both disciplinary and interdisciplinary education for unregulated providers', pre-professionals', and nurses' education. As home care delivery tends to be task-focused (Benzein et al., 2004; Guberman et al., 2006; Ward-Griffin, 2001) and the health care system is currently promoting collaborative health care models (Jansen, 2008; Oandasan et al., 2006) to enhance client and family participation in health care teams, a curricular focus on relational practice for social interaction KT may be particularly relevant. In addition, student and paid care provider application of interactive and critically reflective principles of adult learning (Donaldson et al., 1999; Knowles, 1990; McWilliam, Kothari, Kloseck, Ward-Griffin, & Forbes, 2008) could promote the integration of tacit and experiential care knowledge with research-based UI management knowledge to address client-centered health promotion processes and outcomes.

The theoretical development of social interaction KT theory (Brown & Duguid, 2001; Ferlie, Fitzgerald, Wood, & Hawkins, 2005; Gherardi & Nicolini, 2000) may be enhanced by understandings gained from this study's findings about family caregivers' experience of social interaction KT. Findings within the dialectical patterns of working together/not working together may afford greater understanding of components of social interaction KT models. For example, the sub-themes of working together/not working together illuminate potential facilitation strategies as described in the Promoting Action on Research in Health Services (PARiHS) model (Rycroft-Malone, et al., 2002), while facilitators and barriers identified in the home care context in this study illustrate in depth the significance of context, articulated in the PARiHS Model. Similarly, the patterns of

working together/not working together explicate how the Participatory Action Knowledge Translation (PAKT) (McWilliam et al., 2009) might unfold amongst family caregivers, home care recipients, and paid care providers and how Structuration Theory (Giddens, 1991) may be applicable to the investigation of knowledge boundaries within the process of in-home KT.

The findings of this study have implications for policy as well, making particularly apparent the shortcoming of existing policies that impede KT. Policies that shift from acute and chronic facility-based care to community settings (Fast & Keating, 2000; Romanow, 2002) create heavy caseloads for in-home care providers and caregivers. The lack of financial resources to implement and sustain a community-based health and social care infrastructure to service these increased caseloads is problematic (Health Council of Canada, 2008; McAdam, 2000). Challenges to optimal family caregiving have been associated with per visit funding formulas that do not afford time for in-home care providers to spend with clients and family caregivers for KT (Jansen et al., 2009). As the findings of this study suggest, these challenges extend to KT. As well, policies that promote increasing time for task resource allocation and restricted service allocation, thereby the burden of care assumed by family caregivers may inhibit KT, as such physical demands may overtax caregivers' coping capacity and, in turn, their ability to engage in and benefit from KT (Colling et al., 2003). In as much as both continuity of providers and adequate time for relationship-building facilitate KT through social interaction, policies that enhance financial and human resource allocations are needed to support continuity of the assignment of in-home paid providers and adequate provider time in the home to develop working relationships with family caregivers and care recipients.

Findings from this study merit further exploratory interpretive research to enhance understanding of how social interaction KT transpires between and among in-home family caregivers, care recipients, and paid care providers. Further exploratory research is required to understand in greater depth precisely how family caregivers' perceptions of therapeutic and working relationships with un-regulated providers and interdisciplinary health care team members, continuity of paid provider assignment, and time spent with providers may enter into home care clients' experience of learning about in-home care. Intervention research with professional, para-professional, un-regulated care providers, and family caregivers may be particularly relevant for social interaction KT related to UI management to measure the outcomes of a diversity of KT strategies within the home and in other contexts.

### **Conclusion**

Findings from this interpretive study suggest the importance of relationships and social interaction, in particular, family caregivers and in-home paid care providers working together to create social interaction KT for family caregivers within the home care context. Knowledge translation was experienced as a process of working together/not working together that was relational in nature and contextualized by facilitators and barriers related to both the home care context and the personal attributes of those involved in in-home care. Family caregivers' way of learning to provide UI care may be in contrast to professional providers' traditional approaches of didactic transfer of information.

The findings of this study suggest that family caregiver and home care provider information-sharing within social interactions may play a role in how knowledge is socially created, integrated, and enacted to manage UI and in-home care. However, the

relationship between family caregivers', paid providers', and home care recipients' social interactions and KT requires further exploration. Further interpretive research may help to uncover in greater depth the relational social interaction processes and strategies for KT between and among paid care providers such as professional nurses and unregulated care providers, and unpaid family caregivers and care recipients confronting the challenges of continence promotion and UI. Exploratory interpretive study using Grounded Theory method that investigates the research question, 'How do family paid care providers, family caregivers, and home care recipients enact UI KT within the context of home care?' will aim to create substantive theory of the process of caregiver KT. The following chapter presents this follow-up investigation.

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## CHAPTER FIVE

### TRANSLATING KNOWLEDGE THROUGH RELATING

#### Introduction

Urinary incontinence (UI) is a principal cause of the collapse of informal in-home elder care arrangements and care recipient admission to long-term care (Farage, Miller, Berardesca, & Maibach, 2007; Thomas et al., 2004). Forty-six percent of elderly home care recipients experience symptoms of UI (Du Moulin, Hamers, Ambergan, Janssen, & Halfens, 2008), and this is anticipated to increase with an aging population (Canadian Continence Foundation, 2007). Urinary incontinence, defined as the unintentional excretion of urine (Abrams et al., 2003), can be addressed through conservative treatment and continence promotion (Cheater, 2009; Fader, Bliss, Cottenden, Moore, & Norton, 2010). However, unpaid caregivers who provide personal, social and health care for 98% of older adult family members and friends receiving home care services (Canadian Institute for Healthcare Information [CIHI], 2010) may lack knowledge about continence promotion and management (Jansen & Forbes, 2006). Caregivers, herein referred to as family caregivers, have significant problems managing UI (Brittain & Shaw, 2007).

Knowledge translation (KT) has been defined as a process that includes the creation, exchange, enactment, and application of knowledge within an interactive context to promote health (Canadian Institutes of Health Research, 2009). The KT process has been understood to be informed by pre-existing personal knowledge, experiential learning, and preferred sources of information, all often linked to social interaction (Nutley, Walter, & Davies, 2003). Although research findings to date have suggested that family caregivers experience in-home KT through social interaction (Chapter Four), social process perspectives based in the organizational and professional

KT literature (Brown & Duguid, 2001; Estabrooks, Midodzi, Cummings, Wallin, & Adewale, 2007; Ferlie & Dopson, 2005; Gherardi & Nicolini, 2000; Graham et al., 2006; McWilliam et al., 2009; Scott, Seidel, Bowen, & Gall, 2009) have not been applied to the study of the social enactment of KT by health care providers and health care recipients (Gagliardi, et al., 2011) within community settings (Kothari & Armstrong, 2011). This gap creates uncertainties about knowledge creation, exchange, enactment, and application, hence, how to go about social interaction KT is inadequately informed.

We have limited knowledge of how the social enactment of KT may unfold, and ultimately how it might be promoted, specifically for UI management between and among in-home care professionals, personal care workers and unpaid family caregivers, and those receiving UI care. Not only are both client and family caregiver health ultimately undermined by the strain of unsuccessful UI management (Brittain & Shaw, 2007; Cassells & Watt, 2003), but also UI results in annualized expenditures for families of \$2.6 billion in Canada (Canadian Continence Foundation, 2007) and \$14.2 billion in the United States (Hu et al., 2004). Exploratory research is needed to enhance understanding of the social process of in-home KT.

The aim of this study was to enhance understanding of the social interaction process of KT between and among paid care providers such as professional nurses and unregulated care providers, unpaid family caregivers, and home care recipients confronting the challenges of continence promotion and UI. The research question was: How do paid home care providers, family caregivers, and home care recipients enact UI KT within the context of in-home care?

### **Literature Review**

A literature search using the terms of in-home knowledge translation, community

nursing care, caregivers, social interactions, and urinary continence, was conducted of the online databases of CINAHL, Medline, Embase, Social Work, ERIC, Psych Info and the Cochrane Library for articles published from 1982 to 2011. Eleven research studies were selected as providing insights to inform understanding of the social interaction process of KT between and among family caregivers, home care recipients, and home care providers to manage in-home continence promotion and management. No definitions or references related to KT were found within the in-home family caregiver, care recipient, and paid care provider interaction literature. No studies were found that explored in-home KT specifically as a social interaction process.

Research studies that have focused on role enactment relevant to social interaction KT include qualitative descriptive (Benzein, Johansson, & Saveman, 2004), multi-case (Guberman, Lavoie, Pepin, Lauzon, & Motejo, 2006), and critical ethnographic (Ward-Griffin, 2001) studies. Findings from these studies revealed that nurses perceive their role as that of the expert provider with expectations that family caregivers would provide care and receive prescriptive task-focused education to enable elder care.

In contrast, two qualitative studies (Heinrich, Neufeld, & Harrison, 2003; Sims-Gould & Martin-Matthews, 2010) have found that family caregivers instructed and collaborated with paid providers, functioning in roles similar to those of the home care providers. Thus, to date, studies of role enactment relevant to KT for in-home elder care suggest that both professionals' task-related instruction and expectations of family caregivers' involvement may be part of the social interaction process of KT. Findings also reveal that family caregivers ascribe the same role expectations to themselves, although they describe more proactive collaborative roles with providers. However, these

studies do not elaborate upon how paid providers' and family caregivers' role enactment may have transpired to create social interaction KT.

Research to date also has described family caregivers' expectations of social interaction relevant to KT. In an ethno-nursing study, Van den Brink (2003) found that family caregivers may refuse to use assistive devices if home care education is provided in a prescriptive, didactic way that is incongruent with the family's desire to work and learn through collaboration with paid providers. Findings from a descriptive exploratory sub-study (Schumacher et al., 2002) suggest the essentiality of social interaction as part of family caregivers' ongoing in-home education, while one-time professional didactic teaching was not effective. Findings from phenomenological investigation suggest that social interaction, particularly within working relationships, is an important component of family caregivers' (n=4) experience of KT (Chapter Four). This study, as with the other studies that illuminate family caregivers' expectations of social interaction specific to KT, did not address *how* family caregivers, paid care providers, and home care recipients together relate to socially construct KT.

Three studies have investigated paid providers' social interaction relevant to KT. In a qualitative observational sub-study of 42 family caregiver-care recipient dyadic interactions during bathing care, researchers (Mahoney, Trudeau, Penyack, & MacLeod, 2006) found that: a) direct observation of family caregiver and care recipient interactions during bath time can enhance the paid providers' knowledge of the caregivers' and care recipients' bathing experience, and b) paid providers' and family caregivers' knowledge-sharing can co-create an approach to the bathing process. In addition, family caregiver practice sessions with paid providers may enhance in-home evidence application. While findings suggest a few social interaction strategies and issues relevant to KT, questions

about KT, particularly how to enact KT relevant to UI management, have not been investigated.

A grounded theory study (Jeon, 2004) illuminated that family caregivers' (n=7) and professional nurses' (n=6) knowledge-sharing and collaborative problem-solving created mutual approaches to working together in community settings. Although these study findings may have applicability to in-home KT, particularly as they inform the development of paid provider and family caregiver working relationships, this study did not explicate processes of social interaction informing how to go about KT for the management of UI.

Findings from a quasi-experimental intervention study (Colling, Owen, McCreedy, & Newman, 2003), which tested professional teaching and family caregiver coaching to manage in-home bladder training, demonstrated significant improvement of client-relative UI symptoms and UI care. These findings suggested that the KT approaches were effective. However, the authors reported that these family caregivers were not always able to follow the instructions provided due to other physical and psychological demands of caregiving. This investigation focused on the unidirectional transfer and sharing of knowledge by the paid care providers and did not describe the social interaction KT that may have transpired between the nurses and family caregivers to manage UI. Further family caregiver consultation was recommended to inform approaches to in-home UI KT.

Research findings relevant to social interaction KT suggest the relevance of social processes to in-home KT. However, the literature does not provide an extensive account of how paid care providers, home care recipients, and family caregivers interact to create KT. If we are to enhance understanding of the social process of in-home KT, grounded

theory research is needed to explore how the social enactment of KT may unfold between and among family caregivers, paid care providers, and home care recipients.

### **Methodology and Methods**

Grounded theory method aims to generate a theory that accounts for social interaction patterns that are enacted by participants, in this instance the social interaction process of UI KT among paid providers, unpaid family caregivers, and home care recipients. Grounded theory illuminates the influences that social interactions and social contexts have on the behaviours that emerge from the perspective of those people being studied. Thus, grounded theory is appropriately suited to the investigation of social interaction focused on UI KT.

Symbolic interactionism, that is, reflection on the experience and meaning of interactions in social contexts that may change knowledge of social behavior and social engagement, provides the theoretical perspective for grounded theory research (Glaser & Strauss, 1967). Glaser (1978) emphasizes that data and theory emerge through the analysis of basic social processes without the use of preconceived theoretical frameworks and coding themes. Glaser's approach to grounded theory method afforded clear methods and techniques for constant comparative interpretive analysis of social interaction in process. This choice avoided the limitations of prescribed abstract theoretical procedures (Corbin & Strauss, 2008) or the lack of structured interpretive methods (Charmaz, 2009).

### **Study Context**

This investigation was conducted within a south central rural home care setting of one of the 12 health regions in Saskatchewan, namely the Health Authority Board that is accountable for the health services provided to the 56,000 residents of this region. Home



care, a sub-service of continuing care, is provided to 2,500 clients through an integrated single point of access model for team-based continuing care services. Home care services include: needs assessment and care coordination, home nursing, home health aide services, volunteer services, physiotherapy, occupational therapy, palliative care, respite, intravenous therapy, and Meals on Wheels. Home care team members (nurses, physiotherapists, home health aides, social workers, case managers, and occasionally, physicians) are represented on regional and provincial care, human resource, financial, and information management quality improvement teams to facilitate evidence-based care and service. The health region is committed to the inclusion of family caregivers and care recipients in team-based quality improvement initiatives to increase the quality of life of those who experience UI, and ultimately, the reduction of long-term care admissions and the costs associated with UI management. Approximately 70% of those receiving home care services in the health region experience symptoms of UI. Thus, the health authority that comprised the context of this investigation was committed to working with the researcher to explore KT related to the provision of in-home UI care for older adults.

### **Recruitment and Sampling Strategy**

From a database of the health region's home care service recipients and family caregivers, case managers selected care recipients over the age of 65 and then contacted potential client-family caregiver participants who were involved with managing UI and willing to be contacted by the researcher. Case managers provided letters of information about the study (Appendices D and E) and requested consent from each of the client and caregiver participants to provide their name and telephone number to the researcher.

Contact of the home care paid providers was facilitated by home care office staff who

placed an introductory study letter (Appendix F) in the home care mail boxes of all home care nurses, community therapists, and home health aides. Those client-caregiver participants and home care providers who consented to release their names were contacted by the researcher, who further explained the study and sought formal informed consent for their participation (Appendices G, H and I).

The sampling strategy is not pre-determined in grounded theory (Glaser, 2001). The number of participants was determined by the quality of the participants' experiences, their ability to reflect on and report their experiences of learning how to manage UI and in-home care, and the concepts and constructs that guided further theoretical sampling. Sampling began by purposefully selecting out three family caregivers, care recipients, and paid care providers triads from the sampling frame of family caregiver-client dyads who also had involvement of consenting providers to explore how KT unfolded. To build a grounded theory study of the social process of UI KT, theoretical sampling followed, engaging other participants with the potential to provide greater depth of data related to key concepts and constructs. To build a grounded theory study of the social process of UI KT, theoretical sampling was then initiated with additional participants with the potential to provide greater depth of data related to key concepts and constructs. The intent of theoretical sampling is to identify and refine categories of data through a process of constant comparative analysis throughout the data collection process (Glaser, 1978).

The total sample size of people representing the three groups of participants was determined by the adequacy of data, that is, the extent to which the collected data saturated the categories and components of the grounded theory derived (Glaser, 1978). Sampling ceased when constant comparison of the properties of the emergent categories

revealed theoretical saturation. Theoretical sampling also promoted appropriateness of the sample selection to inform the answer to the research question.

The theoretically-driven sample from this study (n=23) ultimately was comprised of six family caregivers, six home care recipients, and fourteen home care providers. Family caregivers (four females, two males), were the spouses and adult children of the home care recipients, ranged in age from 60 to 88 years ( $\bar{x} = 76$  years), and lived with the care recipients. The six care recipients (three male and three female), who varied in age from 65 to 84 years ( $\bar{x} = 74$  years), experienced UI, chronic illness, and compromised mobility. The female care recipients, who were diagnosed with late-stage dementia, did not contribute verbally to the study, however, were present during their family caregiver's interviews. Home care service duration for personal and nursing care ranged from one to four years ( $\bar{x} = 2.5$  years) and was provided by paid providers (twelve females, two males), who ranged in age from 21 to 65 ( $\bar{x} = 45$  years), and were home health aides (n=7), registered nurses (n=3), and social workers (n=2) or physiotherapists (n=2). Participants represented the predominately Caucasian population of the geographic area and had work experience (one year to 30 years) in urban and rural areas of the health region. Of the home care providers, 21% had an undergraduate degree, 21% had a diploma, and 58% had home care special care aide certification.

### **Data Collection**

Two audio-taped, semi-structured interviews (Appendices J, K and L) lasting one to two hours were used to elicit data explaining what was going on, who was involved, how they were involved, how activities were organized, how the UI KT process unfolded, and what knowledge about UI was contributed by whom, when, where, and how. In addition, observations of interactions occurred if and as potentially relevant KT

interactions transpired within the in-home context amongst the three categories of participants (Appendix M). All interviews were audiotaped and transcribed verbatim for analysis. Field notes explicating subtle nuances of the context in particular, the researcher's questions and observations regarding behaviors, intents, thoughts, understandings, expectations, social interactions and evidence of tacit knowledge were made during each visit.

### **Data Analysis**

Data were analyzed through the constant comparative method of analysis (Glaser, 1978; Glaser & Strauss, 1967). Initially, the data were explored line-by-line through open coding to identify the properties of each unit of data. Next, units of data were compared across content within each interview, across interviews with each participant, and across interviews of all participants. The dimensions of core concepts and categories were generated by constantly comparing concepts and incidents and by seeking the main theme or category revealed by the units of data (Glaser. 1978). Selective coding then was used to identify the basic social process or core variable, to code variables that related to the core variable, and to undertake an ongoing comparison of incidents with the properties and dimensions of these variable categories and the core variable.

Theoretical coding involved examining relationships among categories (Glaser & Strauss, 1973). As theory emerged from the data, constant comparison was used to compare the data with the emergent theory to define dimensions of categories further and to determine if the data supported the categories, core variable, and the relationships of the categories with the core variable. The researcher also searched for data that did not support the emergent categories and theory.

Possible exceptions to the theory, for example age- and gender-related specifics, were monitored by increasing diversity of the sample, thereby expanding an understanding of the actual categories and dimensions and enabling refinement of an interpretation of the findings (Glaser, 1978). Categories were considered to be theoretically saturated when no new dimensions of a category emerged through constant comparative methods. Examination of the literature also occurred during the analysis to inform the emerging theory.

### **Qualitative Rigor**

Glaser's (1978) criteria for judging the rigor of a grounded theory study, including fit, work, relevance, and modifiability, were used to enhance qualitative rigor. Fit relates to the extent to which the categories emerge from the data and represent the underlying data patterns and variation in the behaviors that comprise the basic social process of the grounded theory. Fit was continually refined and strengthened by constant comparisons during data analysis.

Work is defined as the ability of the grounded theory to provide predictions of what occurs in the topic area through explanation of the relationship of categories. The criterion of 'work' also refers to how the relationship of the categories accounts for the basic social process uncovered in the data. To promote the criterion of work, the participants' language was used as much as possible to develop the themes.

The criterion of relevance refers to the extent to which the theory, which is based on theoretical explanation of the relationships between and among categories, informs the key concerns of the respondents, rather than any pre-existing notions of theoretical constructs and relationships. Relevance of this grounded theory study was supported by

selection of participants according to their experiences with UI KT, thereby enhancing the applicability of the theory to the process of in-home UI KT.

The criterion of modifiability was achieved as new data emerged and the researcher modified emerging or established analyses as conditions changed (Glaser & Strauss, 1973). Participants had the opportunity to review the study findings, further inform the themes, and authenticate study findings through member-checking. Guidance for modification of the transcribed and analyzed data also was provided by the student's dissertation committee, who served as peer reviewers. The theory ultimately described in this dissertation has the potential for modifiability in subsequent investigations when new relevant data are uncovered and compared to the existing units of data.

Continual reflection during data collection and analysis entailed the researcher asking her own questions about fit, workability, relevance and modifiability of emergent categories, thus generally promoting the criteria of qualitative rigor and concurrent analysis of the data. Auditability was addressed by maintaining raw data, field notes, and memos, providing an audit trail of the various steps taken throughout the research process. Memoing encouraged critical reflection regarding the meaning and assumptions underpinning data and codes as well as definition and linkage of the properties of categories identified to formulate the theory. Memoing also provided guidance for further coding and theoretical sampling, thereby enhancing the authenticity of the theory discovered through the research process (Glaser, 1978).

### **Ethics Approval**

Ethics approval was obtained from the Health Science Research Ethics Board of the University of Western Ontario and the Behavioral Research Ethics Board at the University of Saskatchewan. The participants were informed that they could refrain from

answering any questions which caused them to feel uncomfortable and/or could withdraw from the study at any time without fear of jeopardizing their access to or continuation of services. Participants also were informed that confidentiality would be maintained with all collected data. All data stored on computers were password protected, and tape recordings, memory keys, and transcripts were maintained in a locked filing cabinet in the researcher's office.

### **Findings: Translating Knowledge Through Relating**

The core variable of 'Translating Knowledge through Relating' constituted the basic social process of in-home KT among family caregivers, home care recipients, and paid home care providers. Figure 5.1 represents the study participants' dynamically evolving and inextricably linked intertwining relational and translating interactions relevant to KT to manage UI and in-home care. The sub-themes of *relating* included: *living with the problem, developing comfort, nurturing mutuality, building confidence, and managing in-home care*. Sub-themes of *translating knowledge* included: *building experiential knowledge, easing into a working relationship, facilitating knowledge exchange, fine-tuning knowledge, and putting it all together*. This substantive theory of social interaction KT theory as comprised by its constituent thematic patterns is presented in the following sub-sections.

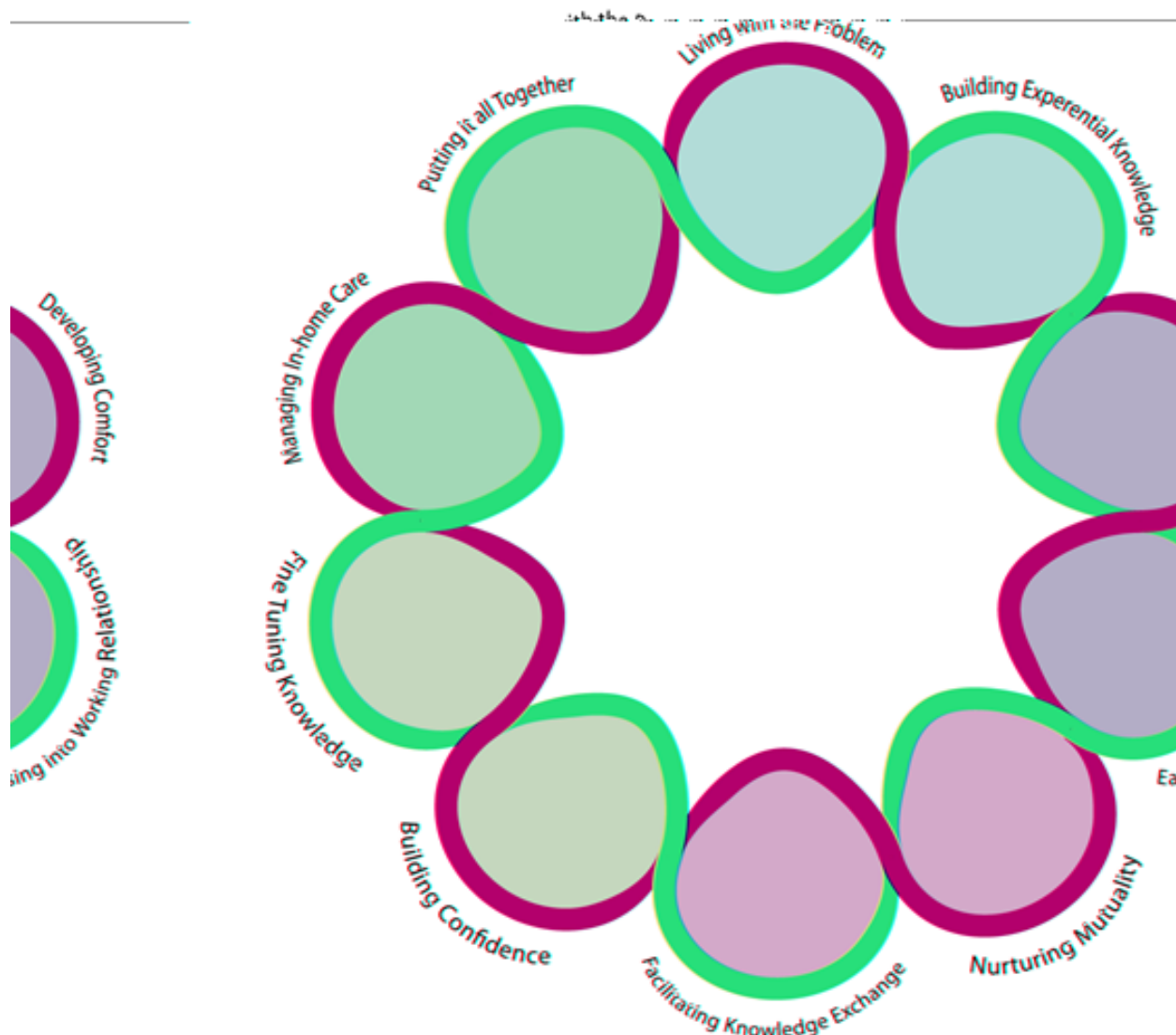


Figure 5.1. Translating Knowledge Through Relating

### Relating

Study participants enacted the process of translating knowledge to manage in-home care through relating to one another. As one home health aide stated: “It’s all about the relationship so that we can help each other learn about in-home care.” Similarly, a family caregiver explained: “We [family caregivers and paid providers] have a relationship. I can share just about anything with them .... We ... learn how to give the



best care together.” Five relational sub-processes emerged from the data as enacted by the study participants.

### **Living with the Problem**

Family caregivers and care recipients socially constructed knowledge for the daily management of UI through their experiential learning of living with the problem and sharing their learning with paid home care providers. One home care recipient described this process: “We [caregiver and care recipient] *refer* to this [information shared by physicians and hospital staff prior to receiving home care] *everyday* to learn about my condition [UI and mobility issues] ... We share this information with the home care people.”

Similarly, paid providers’ experiential learning acquired through the social process of living with the problem, constituted this learning through relating. As one registered nurse explained: “They [care recipients and family caregivers] can be very creative ... because they are living with the problem ... and I will say ... I really learned [UI management] ... from what they shared with me.”

### **Developing Comfort**

Family caregivers and paid providers described developing comfort as a bi-directional social interaction process that was mutually beneficial to family caregivers, care recipients, and paid providers in translating knowledge. One case manager emphasized that developing comfort was essential to translating knowledge through relating, as follows: “If the family caregiver is entering into the sharing and learning process ... you really have to listen to them to promote their comfort and learning.”

A registered nurse explained that paid providers can promote comfort in UI management by discussion: “It [UI] can be addressed .... [We] talk about how to do this so that we promote their [family caregiver and care recipient] comfort.”

Paid providers’ comfort with family caregivers also evolved within the relational interactions of developing knowledge about in-home learning and care processes. As one family caregiver commented: “The new providers are more stressed than we are as caregivers.... The more they come, the more relaxed they become with me. They came to know my ways.”

Participants described the essentiality of a deep relational connectedness which was foundational to the social construction of comfort and the inextricably linked social enactment of KT: As one home health aide shared: “She [family caregiver] is one that I would like to think of as my friend right now. There is a deeper relationship and comfort [between us] ... as we worked together ... we learned how to relate. Another family caregiver described the in-depth relating and knowledge-sharing enacted with paid providers:

I have thought of moving, but the home care staff are our [family caregiver and care recipient] friends – we love them all – I can tell them anything. I don’t want to leave these people. We look forward to them coming in the morning and working with them.

One registered nurse shared her observations about how clients’ trust in the knowledge of un-regulated providers evolved through the relational construction of developing comfort:

Sometimes clients will have a lot of trust in a home health aide ... because the home health aide becomes very familiar with them and the client is comfortable

with the home health aide ... and they know what works [to manage UI]. They [home health aides] are just so much part of their life ... like a friend.

### **Nurturing Mutuality**

The relational process of nurturing mutuality also very much contributed to translating knowledge through relating. According to one family caregiver nurturing mutuality was essential to knowledge-sharing:

Each person [caregiver and paid provider] contributes [to work together], “I’ll do that if you will do that.... Then next time each knows what to do, and we build a little more each time as each of us is familiar with what and how the other does something. It’s a mutual thing because each of us is equal.

One home health aide also described how nurturing mutuality was a relational aspect of KT: “As I worked with the family caregiver and shared my knowledge, I learned that she really knew what she was doing. I did well to take the knowledge that she had to offer.

### **Building Confidence**

The social construction of confidence emerged as part of *translating knowledge through relating*. One home health aide described how building confidence in their own care knowledge was essential in also building family caregivers’ confidence in the providers’ potential for sharing this knowledge: “Providers have to be confident and show family caregivers that we do have knowledge and that we will explain the rationale [for UI management] and listen ... and build their [caregivers] confidence.”

One home health aide shared her social construction of building confidence: “Just make them [family caregivers] feel like they are doing a good job [of learning how to manage UI] ... So I will say, you are doing an excellent job.”

## **Managing In-home Care**

Managing UI and more general in-home care through the relational process of working together was part of translating knowledge through relating. Family caregivers and home care recipients were supported through working relationships to be in control of and manage a chronic condition. One home health aide shared the following insight:

We work with them [family caregivers and care recipients] to support them in the management of UI. For example, I might say: “You can manage ... your condition ... and this is how to do it.” So they are empowered. They take back the control that they have lost.

In summary, these five sub-processes between and among family caregivers, care recipients, and paid care providers constituted the process of relating, an inextricable component of the core variable, *translating knowledge through relating*. The social construction of relating to engage in KT was mutually and affectively enacted through being ‘relationally’ with others.

### **Translating Knowledge**

The social construction of translating was created by building on relational interactions within working relationships. Five sub-themes comprised the sub-processes of translating knowledge.

### **Building Experiential Knowledge**

As part of the social construction of KT, participants’ experiential knowledge evolved through integrating in-home care experience with tacit ‘know how’ knowledge. One home health aide described her preferred way of creating and applying knowledge: “I learn best by doing and experience”. Another home health aide described how she combined her formal and experiential knowledge and then applied this knowledge

through in-home interactions: “I combine my experience or what I have seen across many homes with what I learned more formally. Then I apply this information as I work with people in the home.”

A family caregiver explained how she learned experientially by observing and then performing a care technique:

I learn by doing – I figure out how to do it just by watching ... I was doing it [UI care] in a different way ... But I learned better techniques by watching the care worker so then I could help him [spouse] with moving and skin care.

### **Easing Into a Working Relationship**

Participants emphasized the importance of managing time to ease into social interactions that support learning about and working to co-create approaches to manage UI. As one family caregiver described: “As I ... ease over time into what needs to be done and how I go about it [learn about UI], I involve and work with home care.”

Paid providers also used communication strategies as part of working together to approach the topic of UI. One social worker described how she was able to ease into an in-home working relationship through discussion:

I start with broad assessment.... it assists us in easing into conversation about UI so I commence with questions about mobility, nutrition etc. as we work with them [family caregiver and care recipient].

One home health aide described how managing time for learning through social interaction afforded opportunities for the family caregiver to become comfortable with the paid provider:

It’s hard because I may not have enough time to engage in the social aspect [sharing UI information] and ... work with them to make them [caregiver and

care recipient] comfortable.... So I will tell them that I will be back to see them tomorrow.

Study participants stated that the use of humour with paid providers, family caregivers, and care recipients created relational connections as part of working together to create approaches to care. One home health aide stated:

As we work together ... I realized it was important for him [care recipient] to have a laugh ... it's like connecting with him and giving him a little bit of hope that something can be done to manage his condition.... So I tried to make his day a bit brighter by sharing a bit of humour with him... and then we would talk about how to do his care.

Similarly, a family caregiver emphasized how important it was to incorporate humour as way of creating relational intimacy: “We [caregiver, care recipient, and paid provider] always have a laugh while we work. It gets us to work a bit closer to make the best care for my spouse.”

### **Facilitating Knowledge Exchange**

Paid care providers created opportunities for family caregivers and home care recipients to be part of relational exchanges of care knowledge. As one case manager commented:

I share my observations [about in-home signs of UI] with them [family caregiver and care recipient] and invite them to contribute to the conversation about how to manage UI.... I also teach the clients and then ask them to share with me how that teaching information might work for them.

One home health aide shared how she proactively facilitated knowledge exchange for care management, engaging family caregivers in the process: “I said ... Is something not working? Is there anything we can do differently [to address how to learn]?”

### **Fine-tuning Knowledge**

The fine-tuning of knowledge for chronic care was socially enacted by the bi-directional efforts of the study participants. As one family caregiver commented: “They [paid providers] know and learn my habits [for in-home care] and I learn their habits.

One home health aide stated: “I said, ‘As I work with home care clients, I am explaining as I go ... I explain the reason for doing something [care technique]’.” Another home health aide also illustrated how the refinement of care information transpired through working with a family caregiver and care recipient to co-create a bathing procedure: “This is what we can do. This is what we can’t do. So let’s see how we can get to where we need to go [with lifting into the tub].”

A family caregiver described how she fine-tuned the knowledge she needed to promote continence for her spouse and ultimately assisted the paid providers in understanding how to assist her spouse with toileting:

When home care came in, I always explained to them the situation [what signs the care recipient made when he had to go to the bathroom] and that they would have to help him to the bathroom, ... and so they were able to support him in this regard.

### **Putting It All Together**

Interpersonal interaction was used to build on care knowledge and discover innovations for UI and other chronic care conditions. A family caregiver explained how she and a paid provider together co-constructed and applied integrated knowledge through ‘putting it all together’:

I had an idea about what I thought would work [to manage UI]. She [care provider] came up with another idea but it was not working totally. I expanded on the design of the material by creating a wick to draw the urine away from the skin ...We learned together and put it all together right.

A care recipient described how he and his family caregiver were able to co-create care management knowledge through social interaction with several paid providers: “We compiled a little booklet that talks about the problems with my condition and all of the various things that could go wrong and then refer to this information everyday to learn about my condition, so we put it all together.”

In summary, the substantive theory of *Translating Knowledge Through Relating* revealed bi-directional social construction of KT between and among family caregivers, home care recipients, and paid providers in their relating to manage everyday living with UI and other chronic conditions. Sub-processes of relational interactions and translating knowledge were inextricably linked and continuously evolving to create the process of KT. In addition, two factors within this study contextualized the social enactment of KT: continuity of assignment of paid provider and personal attributes of the KT participants themselves. These contextual elements are described in depth elsewhere (Chapter Four).

### **Discussion**

The interpretive and contextually specific nature of this study limits generalizability of the study findings. In addition, limitations of the study may be related to the researcher’s ability to represent the themes that emerged from participants’ interview data, as well as participants’ ability to describe how in-home KT was socially constructed. Nevertheless, the substantive theory of social interaction KT created from this study provides insights into the social enactment of KT, particularly revealing the



relational and subjective nature of KT between and among paid care providers, family caregivers, and care recipients involved in managing in-home-care. This study invites considerations of Structuration Theory (Giddens, 1991) and the significance of relationship in building the theory of KT. As well, findings inform the Participatory Action KT (PAKT) Model (McWilliam et al., 2009), and the Promoting Action on Research Implementation in Health Services (PARiHS) Theory (Rycroft-Malone et al., 2002).

Structuration Theory posits that social structures, for example, in home care settings create social interactions, which in turn, through their enactment also dynamically shape the social structure of which they are a part, a process known as structuration (Giddens, 1991). As with structuration, the findings of this study suggest that paid providers, family caregivers, and home care recipients' social enactment of KT shapes the social structure of in-home KT, which reciprocally shapes in-home care participants' social structuring of in-home KT. This consideration of the relevance of Structuration Theory to the structural context of social interaction KT suggests further in-depth investigation attending to the context of social interaction KT and its relevance to further refining social interaction KT. Rycroft-Malone et al. (2004) identify context as an essential consideration in KT, further supporting this study's insights regarding the relevance of the consideration and manipulation of context in building the theory and praxis of social interaction KT.

Similar to the PAKT Model (McWilliam et al., 2009) that investigated KT amongst paid home care providers in an organizational context, this study provides insights into how tacit and experiential relational 'ways of being' (Hartrick, 2002; Hartrick-Doane & Varcoe, 2008) are socially constructed within in-home settings. As

discovered in the PAKT model and investigated by others (McWilliam et al., 2009; Yorks, 2005) the findings of this study also substantiate that social interaction KT, in and of itself, may constitute experiential and affective relational enactment of ‘how to’ or craft knowledge. If this is so, prioritizing and attending to relationship-building and maintenance in the provision of in-home care takes on heightened significance as provider-caregiver-client relationships may be essential in optimizing the outcomes of both formal and informal care in this context.

Facilitation of KT is described in the PARiHS model as the professional’s role (Harvey et al., 2002; Meijers et al., 2006) within organizational settings. In this study, facilitation unfolded as a mutual process among professional and un-regulated paid providers, family caregivers and home care recipients, thus illuminating its co-constructed nature. Study findings explicate how an affective and intersubjective stance entered into socially enacted KT among paid home care providers, family caregivers, and care recipients. As well, insights illuminated that developing comfort and nurturing mutuality were essential components of easing into working relationships through the evolving relational connectedness and the social construction of trust, all inextricably essential to knowledge creation and exchange. These findings therefore add to the theoretical understanding of how evidence, defined in the PARiHS model (Rycroft-Malone et al., 2004) as scientific, experiential, and preferred client treatment knowledge, is co-created in home care settings. This additional insight suggests an important new conceptualization of the co-facilitation of KT that merits further investigation and testing to build theory.

The insights gained from this study illuminate that home care clients and paid providers experience as desirable and productive the practice of relating more intimately

within the context of working relationships. In addition, the importance of professionals' intentionality regarding how they relate with others in therapeutic relationships has been described (Forchuk & Reynolds, 2001; McWilliam et al., 1997; Peplau, 1997).

Similarities between KT-related working relationships and therapeutic relationships include a 'sharing of oneself' (Gantert, McWilliam, Ward-Griffin, & Allen, 2009) and knowing of another (Forchuk et al., 2000; Heath, 1998; McWilliam et al., 1997) that transpire through developing comfort (Forchuk et al., 2000), trust (Kitson, 2002; Peplau, 1997; Welch, 2005) and a deeper relational connectedness (Caroline, 1993; Stoltz et al., 2006). These linkages to theory on therapeutic relationships also merit consideration.

Relational connectedness also has been informed by the nature of how professionals and clients work together through 'relational inquiry' (Hartrick-Doane & Varcoe, 2008) and how mutual conscious attention to the art of connecting (McWilliam et al., 1997; McWilliam, 2009) 'at the hyphen' unfolds in a single 'I-Thou' unit (Buber, 1958). However, the empirical and theoretical literature also illuminates how paid provider-client connectedness may be constrained by traditional health care practice that creates and maintains relational boundaries with clients (Gantert et al., 2009), a process known as professional 'distancing' and 'othering' (Boreus, 2006). The significance of relational connectedness in social interaction KT clearly invites further investigation if informal care is to be optimized.

One difference that may exist between KT-related working relationships and therapeutic relationships is in the area of professional boundary setting. In therapeutic relationships, the limited sharing of personal information is encouraged to promote attention to clients' needs rather than the needs of the professional (Peplau, 1997). In this type of relationship, uni-directional client information-sharing may transpire with

professionals' application of prescribed expert knowledge (Ferlie, Fitzgerald, Wood & Hawkins, 2005; McWilliam et al., 2009; Ward-Griffin, 2001; Zoffman & Kirkvold, 2007) through 'methods of care' to the client (McWilliam, 2009). Professionals' therapeutic empathetic understanding of a client's health conditions (Egnew, 2009; Gantert et al., 2009) also may differ from intersubjective understandings co-created by clients and professionals together. The paradigmatic perspective of intersubjectivity reflected in the co-construction of knowledge and mutual enactment of KT conveyed in the grounded theory developed in this study simply characterizes being with the other, as opposed to providing therapeutic care to and for them, and consequently invites a different paradigm of professional being. This insight adds depth to previously articulated theoretical (Hartrick-Doane & Varcoe, 2008) and empirical (McWilliam et al., 2009) understandings. Given its relevance to KT, this professional practice paradigm also merits further investigation.

In this study, intersubjectivity evolved within in-home working relationships and transpired in part through the on-going relational co-construction of exchanging and fine-tuning knowledge for managing UI and in-home care. Paid providers engaged in active questioning of home care clients to elicit their knowledge contributions for the co-creation of in-home KT. Home care clients and paid providers co-created care knowledge by explaining to each other their experiential and tacit knowledge of how they performed care and by working together to refine and enact their collective 'how to care knowledge'. Participants also shared strategies used to enact mutual and equitable knowledge-sharing through in-home relational connectedness and attention to clients' tacit knowledge for managing in-home care (Chapter Four). These 'how to' approaches for KT support previous research (McWilliam et al., 2008; 2009; McWilliam, 2009)

wherein professionals' questioning and creation of opportunities for client knowledge contributions (Graetz & Smith, 2009) constituted strategies for social interaction KT. As such, these findings add to understanding of how home care clients and paid providers socially enact KT through cognitive, behavioural, and affective processes.

The findings from this study provide insights relevant to the social creation of knowledge that build on the interpersonal nature of relating as a fundamental component of 'power with' (Hartrick, 2002) and empowering partnering (McWilliam et al., 1997; McWilliam, 2009) for the promotion of health as a resource for everyday living (McWilliam et al., 2009; Rycroft-Malone et al., 2004). That is, through intentionality and conscious reflection on an intersubjective understanding of clients' health perspectives, experiences, and knowledge, paid providers may facilitate clients' active involvement in social interaction KT and ultimately, the social construction of health. As little is known about these KT-related approaches among family caregivers and home care recipients, further exploratory research may advance understanding of both the theory and practice of relational health promotion.

### **Implications**

The insights gained from this research have several implications for theory-building in KT, particularly informing the essentiality of the structure and process of relational continuity in the home care context for the social creation and enactment of care knowledge. Both relational practice and the professional teaching and learning of social interaction KT may be informed by the insights gained from this study. Further research relevant to the co-construction and enactment of KT may explicate the relevance of social interaction KT to health promotion, thereby enhancing the development of theory in this field.

As well, study findings have implications for macro, or system and organizational level policies and procedures. Policies and procedures related to in-home services delivery need to better convey the significance and utility of attention to relational practice as an inextricable component of in-home KT. For example, policies and procedures for work assignments, currently directed toward achieving minimum provider time allocation for specific tasks, ultimately aimed at achieving efficient human resource deployment, might be revised to accommodate conscious attention to promoting the affective component of care and the continuity of relationships between paid providers and clients with the aim of effective human resource deployment.

Policy enactment that supports relational approaches to social interaction KT at the micro individual home care level is also required. Informal caregivers are prone to social exclusion and health issues (Jansen, 2008; O'Rourke, Cappeliez, & Guindon, 2003) and may lack social support for home care (Forbes & Edge, 2009; Forbes, Montague, Gibson, Hirdes, & Clark, 2011). Therefore, financial and human resource policies that support paid providers' time and educational resources for relational enactment of KT, particularly within in-home working relationships, are needed (Chapter Four).

Study findings also have implications for health professional education. As the findings in this study illustrate, paid providers' affective stance, that is, attending to relational practice (Hartrick-Doane & Varcoe, 2008; Kitson, 2002) with home care clients is foundational to the process of translating knowledge for the promotion of UI management and more general in-home care. Thus, attending to in-home affective relational interactions is essential to complement professional education's focus on communication techniques, which are traditionally understood by professionals as the

sole underpinning of a professional/client relationship (Lussier & Richard, 2008) and used as client-centred methods for cognitive information transfer (McWilliam, 2009). Relational practice to create equitable knowledge exchange (Graetz & Smith, 2009) is required so that clients' experiences and perspectives on care can be more fully a part of the KT process. As such, in-home relational practice may be particularly relevant given the sensitivity associated with understanding how to enact KT to manage UI.

The substantive theory developed in this study supports the observations of other nursing scholars that nursing curricula, as well as interdisciplinary curricula that are inter-professional, need to focus on the social process of relational interactions (Hartrick, 2002), both in preparatory and continuing professional education. Formal and continuing education for unregulated providers, family caregivers, and home care recipients should similarly attend to relational interactions. In addition, adult learning approaches (Donaldson, Rutledge, & Pravikoff, 1999; McWilliam, Kothari, Kloseck, Ward-Griffin, & Forbes, 2008) are needed that promote opportunities to apply knowledge of the substantive theory of '*Translation Knowledge Through Relating*' in practice, thus facilitating the integration of tacit, experiential, and research knowledge related to relational interactions and the social construction of knowledge.

The insights afforded by this investigation also directly inform professional practice. Through promoting mutual intentional reflection on how the bi-directional processes of translating knowledge through relating may unfold, home care providers may enhance their own subjective understanding and intersubjective 'knowing' (McWilliam, 2009) and clients' knowing of how to go about in-home care related to needs such as UI management. In addition, this practice strategy may enhance practice skill in knowing when and how to appropriately share their personal knowledge in the

context of working relationships. Facilitation strategies for affective enactment of KT may include prioritizing attention to relationships in the allocation and provision of in-home time, engaging in listening, sharing knowledge and observations, and inviting clients to discuss and contribute their knowledge and skills as part of working together and ‘power with’ approaches for the social construction of KT.

The findings of this study also illuminate how the practice of *Translating Knowledge Through Relating* may contribute to the promotion of health. In this study, *Translating Knowledge Through Relating* may have promoted home care clients’ and paid providers’ critical reflections, thereby enhancing subjective and intersubjective understanding of practice and care assumptions and how these assumptions may enter into relating with others. As in McWilliam et al.’s (1997; 1999; 2009) empowering partnering approach, conscious attention to and knowing of these assumptions may foster relational interactions that promote paid providers’ and clients’ mutual understanding of clients’ chronic conditions, health knowledge, and opportunities to engage in KT, with resources for everyday living. Ultimately, *translating knowledge through relating* may promote the co-creation and enactment of ‘power with’ approaches for care in general rather than the traditional transfer of health responsibility and information as ‘power to’ home care clients. Clients and paid providers may then consciously and equitably attend not only to the social construction of KT, but also simultaneously, to the promotion of health as a resource for everyday living. Thus, *translating knowledge through relating* is illuminated as being, in and of itself, health promoting (Hartrick, 2002).

The findings from this study merit further exploratory interpretive research to enhance understanding of how translating knowledge through relating may be part of empowering partnering approaches to health promotion, between and among un-



regulated care providers, family caregivers, and care recipients. Exploratory research is required to investigate the application of Structuration Theory to social interaction KT, ultimately including intervention studies, particularly attending to the involvement of unregulated providers within the home care context. Ethnographic studies are required to further elucidate the enactment of intersubjectivity as part of KT-related approaches to health promotion and to uncover similarities and differences between in-home working relationships and therapeutic relationships. As well, the theory of *Translating Knowledge Through Relating* also could inform an intervention that could be tested using a randomized controlled design to investigate outcomes.

### **Conclusion**

The findings from this substantive grounded theory of '*Translating Knowledge Through Relating*' suggest that relational interactions are inextricably interlinked in and essential to translating in-home knowledge of UI management, which is largely tacit, "how to", and experiential knowledge as in nature. The core process and sub-processes of this theory illuminate how an intersubjective affective stance works as an essential component of social interaction KT within in-home settings. This theory adds to the theoretical and practice knowledge about in-home knowledge translation amongst providers, home care clients, and family caregivers. Professional relational practice was illuminated as essential to foster mutual and equitable client social construction of in-home UI KT. This theory has the potential to inform social interaction KT in all health care contexts, as well as chronic care management in general. While further research is needed to refine the theory and practice of KT and its relevance to health promotion, ultimately, the practical application of this theory of '*Translating Knowledge Through*

*Relating*' may constitute an important component of promoting health as a resource for everyday living.

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## CHAPTER SIX

### DISCUSSION

#### Introduction

The overall aim of this two-phase study was to enhance understanding of urinary incontinence (UI) knowledge translation (KT) to inform *how* UI management knowledge might be translated within in-home practice. Such knowledge might inform and support family caregivers' and older home care recipients' efforts to address the challenges of providing UI care. The first study explored family caregivers' experience of KT related to continence management. The second study explored the process of KT between and among paid care providers (such as professional nurses, unregulated care providers), unpaid family caregivers, and care recipients in the context of these challenges. The studies were conducted in a rural health region in Saskatchewan, Canada, in which home care, a sub-service of team-based continuing care, provides assessment and care coordination, medical, nursing, rehabilitation therapy and personal care to 2,500 clients.

The interpretive phenomenological approach used in the first study advanced understanding of family caregivers' contextualized experience of KT. Knowledge translation was experienced by family caregivers as a relational process of working together/not working together, contextualized by facilitators and barriers related to both the home care context and the personal attributes of those involved in in-home care. Building on the findings from the first study, the substantive theory of '*Translating Knowledge Through Relating*' was created in the second study, using grounded theory methods. The core process and sub-processes of this theory illuminated in greater depth new knowledge that advances KT theory and the social construction of practical care knowledge. Findings illuminated an intersubjective stance as an essential component of

KT between and among family caregivers, care recipients, and paid home care providers. Relating and connecting through social interaction emerged as inextricable and essential process components to translating the tacit 'how to' experiential knowledge of UI and in-home care. Ultimately, these study findings may inform theoretical and practical approaches to promoting health. The intent of this chapter is to discuss these findings and how the insights gained advance disciplinary understanding of KT and the implications for practice, education, and future research.

### **The Dynamic Nature of Family Caregivers' Experience of KT:**

#### **Working Together/Not Working Together**

In the first study, the social interaction of working together/not working together was uncovered, revealing the complex, dynamic nature of family caregivers' experience of affective KT. The dialectical patterns of in-home working relationships were characterized by *compromising/not compromising, appreciating/not appreciating, understanding/not understanding, encouraging knowledge seeking/impeding knowledge seeking, listening/not listening, and trusting/not trusting* all of which constituted the experience of KT for managing in-home care.

Many of the social interaction components of working together/not working together uncovered in this study have been observed in previous research. Compromising approaches to care and listening have been identified in research that explored family caregivers' educational experiences and knowledge-seeking for in-home chronic care (Jeon, 2004; Paun, Farran, Perraud, & Loukissa, 2004; Stoltz, Lindholm, Uden, & Willman, 2006). Others (Mahoney, Trudeau, Penyack, & MacLeod, 2006) have suggested that paid providers' acknowledgement of the emotional and physical decline of the care recipient, and recognition of caregivers' burden of care were part of family

caregivers' experience of 'trusting of the provider' and ultimately, their experience of in-home KT.

This study revealed that the affective exchanges of appreciation for paid care providers' and family caregivers' in-home care efforts were part of working together to construct KT. Kellet and Mannion (1999) also have described processes of 'appreciating and understanding' family caregivers' knowledge within family caregiver and paid care provider relationships. The findings of this study therefore are congruent with those of several other studies, and further illuminate the experience of KT as a relational bi-directional process, particularly for UI KT, a previously unexplored topic.

Similar to the Participatory Action KT Model (McWilliam et al., 2009) that was uncovered through the exploration of KT amongst paid home care providers in an organizational context, the findings of this study explicate how affective approaches to social interaction KT construct 'how to' or craft knowledge. Given these insights, prioritizing and attending to relationship-building and maintenance in the provision of in-home care take on heightened significance, as provider-caregiver-client relationships may be essential in optimizing the outcomes of both formal and informal care in this context.

### **The Social Construction of Relational Knowledge Boundaries**

The social interaction patterns of working together/not working together that emerged from this study afford insights into how power differentials constituted by paid care providers' knowledge bases may create relational knowledge boundaries between family caregivers and home care providers. Knowledge is considered to be a form of power (Denis, Hebert, Langley, Lozeau, & Trottier, 2002; Hartrick Doane & Varcoe, 2008; Moghimi, 2007). As well, social structures such as home care agencies, are thought to create power relations within in-home social interactions, which through their

enactment (Giddens, 1991), also dynamically shape the social structure of which they are a part. As the findings of this study reveal, within the context of formalized in-home care, family caregivers may experience the structure of relational knowledge boundaries and the agency of relational knowledge, hence power, in paid providers' expert-driven teaching methods and failure to listen to family caregivers' perspectives on care approaches. Such experiences of relational knowledge boundaries have been observed in previous research (Oudshoorn, Ward-Griffin, McWilliam, 2007; Van den Brink, 2003; Ward-Griffin 2001). In addition, didactic educational interactions with family caregivers have been linked with caregivers' mistrust of paid providers (Jeon, 2004; Neufeld, Harrison, Stewart, & Hughes, 2008) and providers' limited understanding of in-home family caregivers' ways of learning (Heinrich, Neufeld, & Harrison, 2003; Van den Brink). Ultimately, this may be experienced as family caregivers' perceived inability to engage in knowledge-seeking.

As family caregivers' experience of relational knowledge boundaries previously has not been explored in the literature in a comprehensive way, these insights add to the knowledge in this field. However, further in-depth exploration of how a structural context might enter into family caregivers' and paid providers' social construction of KT as part of working together/not working together merits investigation. This study's finding of the contextual nature of social interaction KT and its relevance to further refining KT also further illuminates the relevance of context as an essential consideration in KT within the Promoting Action on Research Implementation in Health Services (PARIHS) Theory (Rycroft-Malone et al., 2004).

Family caregivers' experience of relational boundaries in this study also illuminates home care clients' preferred way of interactive learning which may contrast

with more traditional didactic professional transfer of content information to home care clients. Such insights suggest the potential of departure from passive knowledge dissemination efforts to promote KT within in-home settings, in congruence with previous research suggesting that family caregivers expect to engage in KT for professional care knowledge (Goldschmidt, Schmidt, Krasnik, Christensen, & Groenfold, 2006) and to co-create knowledge for self-care (Thorne, Paterson, & Russell, 2003). As well, the findings of this study add to knowledge about the cognitive and behavioural enactment of KT intervention (Eccles, Grimshaw, Walker, Johnston, & Pitts, 2005), revealing a relational affective stance to be a component of KT.

### **Contextual Facilitators and Barriers**

As described by others (Gantert, McWilliam, Ward-Griffin, & Allen, 2009; Peplau, 1997), this study further illuminated how continuity of paid provider assignment and adequate time for the formal service provision of home care were necessary to develop working relationships. Together with the perceived personal attributes of home care providers and family caregivers themselves, these contextual components entered into family caregivers' experience of KT. Insights gained about the essentiality of context within the KT process add to our understanding of the social construction of knowledge.

### **Personal Attributes**

Participants identified the following personal attributes that entered into their experience of KT: *respect toward the other; expectations of the other; sensitivity toward one another; self-expectations for KT; inability to communicate knowledge needs; patience with other; and authoritative stance*. Several of these family caregivers' and paid providers' relational attributes, such as respect and sensitivity, parallel those found in the theoretical and research literature regarding interpersonal and therapeutic



relationships (Forchuk & Reynolds, 2001; Peplau, 1997; Welch, 2005). Family caregivers' experience of inability to articulate knowledge needs and paid providers' inability to convey respect to informal family caregivers throughout the process of achieving KT have not been reported previously. These particular findings may constitute a significant contribution to the literature, as they illuminate how relevant personal attributes may be to family caregivers' experience of KT and how these attributes may enter into the bi-directional process of KT. This insight suggests the importance of an individualized person-centred approach in the practice of KT.

### **Continuity of Assignment**

The relevance of continuity in provider assignments to the building of provider-caregiver relationships, and in turn, the experience of KT was particularly apparent in the findings of this study of KT. This too, is congruent with the findings of previous researchers, who have revealed the need for home care providers to have more in-home paid provider time and continuity for relationship development (Gantert et al., 2009). Peplau (1997) also asserted that continuity of interpersonal interactions and relationships constitutes much of the practice of nursing, wherein nurses apply knowledge of clients through connecting with them to understand and assist with problem solving to address their health challenges. Knowledge translation to promote optimal care is such a challenge.

Other studies have found that lack of client familiarity with the paid providers due to discontinuity of provider assignment (Woodward, Abelson, Tedford, & Hutchinson, 2004) contributes to the inability of family caregivers to transfer client care information to paid providers, particularly for those clients with complex chronic care conditions (Sims-Gould & Martin-Matthews, 2010). Limited continuity in paid provider assignment

also has been linked to the absence of educational guidance to meet family caregivers' needs for knowledge enabling them to manage in-home elder care (Forbes et al., 2008; Forbes & Neufeld, 2008).

### **Working Together Over Time**

In this study, family caregivers described how working with paid care providers and care recipients over time was necessary to learning about UI and in-home care. Family caregivers perceived that time enabled them to reflect on and understand different perspectives associated with UI teaching and learning approaches. When paid providers and family caregivers had little time together, family caregivers perceived their development of trust in the paid provider's ability to apply knowledge about the client and ultimately, KT, to be impeded. Conversely, trust, perceived as a component of relating to and caring for the other, evolved as the paid care provider spent time with the family caregiver and care recipient. During this time, family caregivers observed whether or not the paid care providers applied knowledge of the care recipient's needs to client care.

The context of home care and personal attributes of the participants themselves emerged as inseparable from KT. When paid providers were scheduled to maintain continuity of assignment and when personal attributes enabled the paid care provider, family caregiver, and care recipient to enact relational social processes, KT was facilitated. However, when continuity of assignment did not transpire, and when personal attributes created barriers to the enactment of relational social processes, KT was impeded. Adding to previous research, this study has provided additional in-depth insights into the contextual components of home care related to family caregivers' experience of working together to achieve UI KT, and added to the theoretical foundation

of KT, specifically illuminating the nature of context within the social construction of KT.

As well, this interpretive research has informed understanding and the refinement of approaches to KT within the context of aging and chronic illness, particularly the management of UI. Insights were gained into the importance of relating within complex social interaction processes that are part of family caregivers' experience of KT. The findings of this study illuminate social interaction, particularly within working relationships, and the context of KT as essential components of KT. Attending to the social construction of KT, may foster the use of evidence, that is, the whole of practice 'how to', experiential, relational, and research knowledge (Kitson et al., 2008), thereby potentially enhancing in-home practice and care.

### **Translating Knowledge Through Relating**

Adding to the knowledge gained from the first study, the findings from the second study further illuminated in greater depth how knowledge is socially constructed between and among family caregivers, home care clients, and paid home care providers, thus advancing the theory of KT. The core variable of 'Translating Knowledge through Relating' constituted the basic social process of in-home KT among study participants. Figure 5.1 represents the participants' dynamically evolving and inextricably linked intertwining relating and translating interactions relevant to KT to manage UI and in-home care. The sub-themes of *relating* included: *living with the problem, developing comfort, nurturing mutuality, building confidence, and managing in-home care*. Sub-themes of *translating knowledge* included: *building experiential knowledge, easing into a working relationship, facilitating knowledge exchange, fine-tuning knowledge, and putting it all together*. Study findings about context and the significance of relationship in

KT advance theoretical understanding of KT, and invite consideration of Structuration Theory (Giddens, 1991). As well, findings afford additional insights relevant to the PAKT Model (McWilliam et al., 2009), and the PARIHS Theory (Rycroft-Malone et al., 2002).

### **Insights Relevant to KT Theory**

The findings of this study reveal how paid providers, family caregivers, and home care recipients shape the social structure of in-home KT, through working relationships, which in turn reciprocally shape in-home care participants' social structuring of in-home KT, an insight that illuminates the relevance of Structuration Theory (Giddens, 1991). Insights gained from this study also support the relevance of the consideration and manipulation of context in building the theory of social interaction KT (Rycroft-Malone et al., 2004). These insights suggest potential directions for in-depth investigation relative to the theory and praxis of KT.

Study findings also illuminated how tacit and experiential relational 'ways of being' (Hartrick, 2002; Hartrick-Doane & Varcoe, 2008) are inextricably interlinked essential elements of translating in-home knowledge of UI management. As discovered by others (McWilliam et al., 2009; Yorks, 2005) the findings of this study also support that social interaction KT, in and of itself, may constitute experiential and affective relational enactment of 'how to' or craft knowledge. These findings add to knowledge about how an intersubjective affective stance works as an essential component of social interaction KT (Chapter Four) and how practice knowledge enters into and is interpreted as part of research evidence (Nutley, Walter, & Davies, 2003) for in-home care management.

The social interaction approach to KT may offer a more inclusive and meaningful way than do prescriptive teaching approaches for applying in-home care evidence,

enabling the refinement of practice and the subjective and intersubjective understanding inherent within practice (Benner & Sutphen, 2007; McWilliam et al., 2009). Prioritizing and attending to building and maintaining relationships in the provision of in-home care takes on heightened significance if one considers provider-caregiver-client relationships to be essential in optimizing the outcomes of both formal and informal care in this context.

In this study, KT unfolded as a mutual process among professional and unregulated paid providers, family caregivers and home care recipients, thus illuminating its co-constructed nature. This adds new insights about the facilitation of KT, attributed singularly in the PARiHS model as the professional's role (Harvey et al., 2002; Meijers et al., 2006) within organizational settings. As well, insights arising from this study illuminate that developing comfort, connecting, building trust, and nurturing mutuality as essential components of easing into working relationships that constituted KT. Study findings also add to the theoretical understanding of how evidence, defined in the PARiHS model (Rycroft-Malone et al., 2004) as scientific, experiential, and preferred client treatment knowledge, is co-created in home care settings. Specifically, relational interactions interlinked with tacit and experiential knowledge may co-create and co-facilitate the translation of evidence for UI and chronic care. The reported gap in the use of research knowledge may in part be attributed to a focus on codified knowledge to the exclusion of other forms and ways of knowing (Scott-Findlay & Pollock, 2004) such as tacit and experiential knowledge. This additional insight suggests an important new conceptualization of the co-facilitation of KT that merits further investigation and testing to build the theory of social interaction KT.

### **Working Relationships/Therapeutic Relationships**

The insights gained from this grounded theory study illuminate how home care clients and paid providers experience as desirable and productive the practice of relating more intimately within the context of working relationships that constitute KT. The importance of intentionality in building of therapeutic relationships has been described previously (Forchuk & Reynolds, 2001; McWilliam et al., 1997; Peplau, 1997).

Similarities between KT-related working relationships and therapeutic relationships include a ‘sharing of oneself’ (Gantert et al., 2009) and knowing of another (Forchuk et al., 2000; Heath, 1998; McWilliam et al., 1997) that transpire through developing comfort (Forchuk et al., 2000), and ease as part of working together for the social construction of KT. As well, evolving trust (Kitson, 2002; McWilliam et al., 1997; Peplau, 1997; Welch, 2005), maintaining relational continuity within nursing practice (Peplau, 1997), supporting a deeper relational connectedness (Caroline, 1993; Stoltz, Lindholm, Uden, & Willman, 2006), and working with clients in equitable ways rather than ‘doing things to’ or enacting ‘power over’ approaches in professional practice (Coatsworth-Puspoky, Forchuk, & Ward-Griffin, 2006) have been referred to within the theoretical and empirical literature regarding professional-client relationships. The findings of this study uncover the specific relevance of relationships to KT.

One difference between therapeutic relationships and KT-related working relationships of note is the limited sharing of personal information that is encouraged in therapeutic relating to promote attention to clients’ needs rather than the needs of the professional (Peplau, 1997). The meaning of professional therapeutic empathetic understanding of a client’s health conditions (Egnew, 2009; Gantert et al., 2009) also may differ from that of an intersubjective understanding co-created by professionals and

clients together as was discovered within the substantive theory of the KT process uncovered in this investigation. These linkages to and possible differences between KT-related working relationships and therapeutic relationships merit further consideration.

### **Professional Connectedness/Professional Distancing**

The relational connectedness or intimacy of working relationships uncovered in this investigation of the KT process has parallels with the nature of how professionals and clients work together through ‘relational inquiry’ (Hartrick-Doane & Varcoe, 2008) and how mutual conscious attention to the art of connecting (McWilliam, 2009) ‘at the hyphen’ unfolds in a single ‘I-Thou’ unit (Buber, 1958). This study illuminated how paid providers’ approaches to KT fostered home care clients’ relational perceptions of the paid provider and how intimacy and closeness evolved as part of social interaction KT. This insight into the meaning of relational interactions relative to the purpose, value, and process of social interaction KT to paid providers and home care clients further informs both the theory and practice of social interaction KT.

However, the findings of this study, supported by both empirical (Gantert et al., 2009) and theoretical literature (Boreus, 2006) also illuminate how paid provider-client connectedness may be constrained by the work context and the process of in-home care. Professional ‘distancing’ and ‘othering’ may contribute to uni-directional information-sharing and application of prescribed expert knowledge (Ferlie, Fitzgerald, Wood & Hawkins, 2005; McWilliam et al., 2009; Ward-Griffin, 2001; Zoffman & Kirkvold, 2007) through ‘methods of care’ to the client (McWilliam, 2009). As these findings contrast with traditional approaches to KT, they may inform strategies for social interaction KT. The significance of relational connectedness in social interaction KT clearly invites further investigation if informal care is to be optimized.

### **Interpersonal Nature of Relating: ‘Power With’ for the Social Process of KT**

The findings from the substantive theory of *Translating Knowledge Through Relating* provide insights relevant to the social creation of knowledge. The theory portrays the interpersonal nature of relating as a fundamental component of ‘power with’ (Hartrick, 2002) and empowering partnering (McWilliam et al., 1997; McWilliam, 2009) for the promotion of health as a resource for everyday living (McWilliam et al., 2009). Through intentionality and conscious reflection on an intersubjective understanding of clients’ health perspectives, experiences, and knowledge, paid providers’ reflective inquiry as part of relational practice may facilitate clients’ active involvement (Hartrick-Doane & Varcoe, 2008) and partnering for the social construction of KT and ultimately, health. A ‘power with’ approach to the process of KT with family caregivers and clients changes the focus of content, traditionally viewed as the integration of the patients’ health care perspectives within ‘self-care management’ techniques, and transferring ‘power to’. Clearly, conscious reflection in action on how one is with another throughout social interaction aimed at KT may refine the practice of KT.

### **Intersubjectivity**

The paradigmatic perspective of intersubjectivity reflected in the co-construction of knowledge and mutual enactment of KT simply characterizes being with the other, as opposed to providing therapeutic care to and for them, and consequently invites a different paradigm of professional being. Illumination of the paradigmatic perspective of subjectivity and intersubjectivity promotes understanding of this perspective within the social construction of KT. As this insight has been addressed in a limited way theoretically (Hartrick-Doane & Varcoe, 2008) and empirically (McWilliam et al., 2009), this professional practice paradigm also merits further investigation relevant to KT.



Intersubjectivity evolved within in-home working relationships observed in this investigation, transpiring in part through the on-going relational co-construction of exchanging and fine-tuning of knowledge for managing UI and in-home care. Paid providers engaged in active questioning of home care clients to elicit their knowledge contributions for the co-creation of in-home KT. Home care clients and paid providers co-created care knowledge by explaining to each other their experiential and tacit knowledge of how they performed care and by working together to refine and enact their collective ‘how to care knowledge’. Participants also shared strategies used to enact mutual and equitable knowledge-sharing through in-home relational connectedness and attention to clients’ tacit knowledge for managing in-home care (Chapter Four). Thus, study findings elucidate how intersubjectivity as a shared understanding of a phenomenon (Cody, 1995) promotes authentic re-presentation of shared meaning. Knowing and knowledge are thus emergent, relative, and changing within to the context (Lincoln and Guba, 2000) in which they unfold.

The ‘how to’ approaches that have been elucidated for KT in this study support previous research (McWilliam et al., 2008; 2009; McWilliam, 2009) wherein professionals’ questioning and creation of opportunities for client knowledge contributions (Graetz & Smith, 2009) co-constructed strategies for social interaction KT. Ultimately, family caregivers and providers co-created UI and in-home care knowledge through practice, learning, and working together. Paid provider enactment of relational social interaction processes such as listening to family caregivers and appreciating caregivers’ elder care knowledge may enhance their own and family caregivers’ learning about UI and more general in-home care. Thus, on-going attention to the nature of relating may inform both the social construction of KT and its content.

Family caregivers also perceived that KT came about by reflecting and discovering experientially with others what creates successful quality care (Chapter Four). As such, these findings add to understanding of how home care clients and paid providers socially enact KT through cognitive, behavioural, and affective processes.

The interpretive and contextually specific nature of this study limits generalizability of the study findings. In addition, the researcher's ability to represent the themes that emerged from participants' interview data, as well as participants' ability to describe how in-home KT was socially constructed do limit findings. Nevertheless, the substantive theory of social interaction KT created from this study provides insights into the social enactment of KT, particularly revealing how the relational and subjective nature of KT unfolds between and among paid care providers, family caregivers, and care recipients involved in managing in-home-care.

### **Implications**

The insights gained from this research have several implications for theory-building in KT, particularly suggesting the essentiality of the structure and process of relational continuity in the home care context for the social creation and enactment of care knowledge. As such, study findings advance the disciplinary knowledge base regarding both relational and evidence-based practice and the professional teaching and learning of social interaction KT.

As well, study findings have implications for macro, or system and organizational level policies and procedures. Policies and procedures related to in-home services delivery could better accommodate the significance and utility of attention to relational practice as an inextricable component of in-home KT. For example, policies and procedures for work assignments, currently directed toward achieving minimum provider

time allocation for specific tasks and toward achieving efficient human resource deployment, might be revised to accommodate conscious attention to promoting the affective component of care and the continuity of relationships between paid providers and clients.

Policy enactment that supports relational approaches to social interaction KT at the micro individual home care level is also required. Informal caregivers have been found to be vulnerable to social exclusion and health issues (Jansen, 2008; O'Rourke, Cappeliez, & Guindon, 2003) and may lack the social support they need in order to provide home care (Forbes & Edge, 2009; Forbes, Montague, Gibson, Hirdes, & Clark, 2011). Policy makers might consider attending to the financial and human resource policies that support paid providers' time and educational resources for relational enactment of KT.

Study findings also have implications for health professional education. As the findings in this study illustrate, paid providers' affective stance, that is, attending to relational practice (Hartrick-Doane & Varcoe, 2008; Kitson, 2002) with home care clients is foundational to the process of translating knowledge for the promotion of UI management and more generally for in-home care. Thus, attending to affective relational interactions of in-home care may augment professional education's focus on communication techniques, often the sole underpinning of professional/client relationships (Lussier & Richard, 2008). Relational practice to create equitable knowledge exchange (Graetz & Smith, 2009) may enable clients' experience and perspectives on care to be more fully a part of the KT process.

The substantive theory developed in this study supports the observations of other nursing scholars that nursing and interdisciplinary curricula that are inter-professional,

need to focus on the social process of relational interactions (Hartrick, 2002), both in preparatory and continuing professional education. Formal and continuing education for unregulated providers, family caregivers, and home care recipients should similarly attend to relational interactions. In addition, adult learning approaches (Donaldson, Rutledge, & Pravikoff, 1999; McWilliam, Kothari, Kloseck, Ward-Griffin, & Forbes, 2008) may afford opportunities to apply content knowledge of *Translating Knowledge Through Relating* in practice, thus facilitating the integration of tacit, experiential, and research knowledge related to relational interactions, relational connectedness, and the social construction of knowledge.

The insights afforded by this investigation also directly inform the professional practice of KT. Facilitation strategies for the affective enactment of KT may include prioritizing attention to relationships in the allocation and provision of in-home time, engaging in listening, sharing knowledge and observations, and inviting clients to discuss and contribute their knowledge and skills as part of working together in a ‘power with’ relational approach to KT.

The findings of this study also illuminate how the in-home practice of *Translating Knowledge Through Relating* may contribute to the promotion of health. Translating knowledge through relating may promote home care clients’ and paid providers’ critical reflections, thereby enhancing subjective and intersubjective understanding of practice and care assumptions and how these assumptions may enter into relating with others. As in McWilliam et al.’s (1997; 1999; 2009) empowering partnering approach, conscious attention to and knowing of these assumptions may foster relational interactions that promote paid providers’ and clients’ mutual understanding of clients’ chronic conditions, health knowledge, and opportunities to engage in KT, with resources for everyday living.

Ultimately, *Translating Knowledge Through Relating* may promote the co-creation and enactment of ‘power with’ approaches for care in general rather than the traditional transfer of health responsibility and information as ‘power to’ home care clients. Clients and paid providers may then consciously and equitably attend not only to the social construction of KT but also simultaneously, to the promotion of health as a resource for everyday living. Thus, *Translating Knowledge Through Relating* is illuminated as being, in and of itself, health promoting (Hartrick-Doane & Varcoe, 2002).

The findings from this study merit further exploratory interpretive research to enhance understanding of how translating knowledge through relating may be part of empowering partnering approaches to health promotion, between and among unregulated care providers, family caregivers, and care recipients. Exploratory research is required to investigate the application of theory to social interaction KT, ultimately including interventions studies, perhaps particularly attending to the involvement of unregulated providers. Ethnographic studies are required to further elucidate the enactment of intersubjectivity as part of KT-related approaches to health promotion and to uncover similarities and differences between in-home working relationships and therapeutic relationships. Further research relevant to the co-construction and enactment of KT may explicate the relevance of social interaction KT to health promotion, thereby enhancing the development of theory in this field. As well, the theory of *Translating Knowledge Through Relating* also could inform an intervention that could be tested using a randomized controlled design to investigate outcomes.

### **Conclusion**

The findings from this two-phase study suggest that relational interactions are

inextricably interlinked in and essential to translating in-home knowledge of UI management. Such knowledge is largely tacit, “how to” and experiential as in nature. The core process and sub-processes of this theory, ‘*Translating Knowledge Through Relating*’ illuminate how an intersubjective affective stance works as an essential component of social interaction KT within in-home settings. This theory adds to theoretical, contextual, and practice knowledge about the social construction of KT amongst providers, home care clients, and family caregivers. Professional relational practice was illuminated as essential to foster clients’ active and equitable involvement in the mutual social construction of in-home UI KT for the in-home enactment and application of practical care knowledge. This theory has the potential to inform social interaction KT in all health care contexts, as well as chronic care management in general. While further research is needed to refine the theory and practice of KT and its relevance to health promotion, ultimately, the practical application of this theory of *Translating Knowledge Through Relating* may constitute an important component of client-centred approaches for promoting health as a resource for everyday living.

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Appendix A  
Letter of Introduction for Caregivers



The Experience of Family Caregiver Knowledge Translation

Case Manager or Home Care Nurse will telephone and/or visit family caregivers using the information in this letter to obtain consent for release of the caregiver's name to the researcher.

The Five Hills Health Region is working with a Doctoral nursing student from the University of Western Ontario who is also a nursing professor at the University of Saskatchewan, College of Nursing, Regina site. The purpose of the research is to study family caregivers' experiences of sharing knowledge and learning how to go about the management of in-home bladder control care for older adults they care for in their home. The results of this study may help home care programs and other health care agencies to improve health services delivery for clients who need help with bladder control, and their family caregivers. You, as the family caregiver, are invited to take part in this study.

If you agree to take part, we will provide your name to the researcher, Lynn Jansen, a nurse, who is conducting the research study in partial fulfillment of a doctoral degree in nursing. Mrs. Jansen will phone you and arrange a visit to your home at a time convenient to you to ask you about your experience managing loss of bladder control in a family member. You will be asked to participate in a minimum of two interviews. Each interview will take about one to one and a half hours of your time. Your answers will be strictly private and confidential.

Can we provide your name to the researcher?

I consent to the release of my name to Mrs. Lynn Jansen, who is conducting a research study in partial fulfillment of a doctoral degree in nursing.

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(Signature of Caregiver)

(Date)

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(Signature of Home Care Staff)

(Date)

Appendix B  
Caregiver Consent Form



The Experience of Caregiver Knowledge Translation

What This Study is About:

The Five Hills Health Region is working with a researcher who is an Assistant Professor of Nursing at the University of Saskatchewan, College of Nursing and a doctoral nursing candidate at the University of Western Ontario. This research is being conducted in partial fulfillment of the degree of doctor of philosophy in nursing. The nursing student would like to ask you to take part in interviews in your home. The interviews will be about your experience with sharing information and learning about being a caregiver of someone who has difficulty with bladder control. The results of this study may help home care programs and other health care agencies to improve health services delivery for clients with loss of bladder control and their family caregivers. As a caregiver, you are invited to take part in this study.

What Being in This Study Means for You:

Your participation in this study may help home care and other health care agencies to improve health services for clients who need help with bladder control. However you may not benefit personally from your participation. If you agree to take part, you will be telephoned by the researcher, who will arrange a minimum of two visits to your home at a time convenient to you. During the visits, you will be asked a series of questions during a tape-recorded interview about your experience of acquiring learning regarding being a caregiver of someone who has difficulty with control of their bladder. Each visit will take about 1 ½ hours of your time.

Questions you will be asked will focus on your experience of providing care for someone with bladder control difficulties and your experience with information and education about bladder control care. You may choose to not answer any of these questions. If you do answer them, your answers to these questions will be kept confidential. No names or identifying information will appear on the transcript that is created from the audiotape or within any research reports which may contain interview quotes from this study. A code number will be assigned to the transcript to ensure anonymity. Tape recordings and transcripts will be kept in a locked filing cabinet. Following completion of the study, the researcher may continue to review your interview information contained on the de-identified transcripts from this study. This process is known as secondary analysis and may be done to gain more understanding of the



interview information obtained from your experience of acquiring learning about bladder control care. By consenting to participate in this study, you agree to the researcher doing future secondary analysis with your interview data. Transcripts and audiotapes will be kept for a maximum period of seven years, at which time the audiotapes will be erased and the transcripts will be destroyed. None of this information will be put in any records of the care in the home of the person for whom you are a caregiver.

The researcher may wish to contact you in the future to participate in a new research study. You can indicate whether you wish to be contacted by the researcher for future research by checking a box at the end of this consent form. If you do wish to be contacted by the researcher your name and contact information will be maintained on a file locked in a filing cabinet separate from the de-identified interview transcript data obtained in this study. Your name and contact information will be maintained for a maximum period of seven years at which time your name and contact information will be destroyed.

#### Actions to Protect Your Rights:

Taking part in this study is voluntary. You may refuse to take part, refuse to answer any questions, or withdraw from the study at any time with no effect on your in-home services and care. If you decide to withdraw from the study it may not be possible to erase your tape-recorded interviews and destroy your data transcripts if your interview information has been de-identified. There is a risk that you may get tired or upset from answering these questions. If you do get tired, the interviewer will provide you with a break or stop the interview and come back to finish it at another time convenient to you. If you are upset, the researcher will provide a list of community resources to assist you and she will call your case manager with your permission to arrange any care you need to address the problem.

This letter is yours to keep. If you agree to take part in this study, you will be asked to sign a consent form. You will receive a copy of the consent form after it has been signed. Representatives of the University of Western Ontario Health Sciences Research Ethics Board or University of Saskatchewan Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

This study has been reviewed and approved by the University of Western Ontario Human Subject Research Ethics Board on April 30, 2009 and reviewed and approved by the University of Saskatchewan Behavioural Research Ethics Board on May 25, 2009. If you have any questions about the conduct of this study or your rights as a research subject, you may contact the Office of Research Ethics, The University of Western Ontario, or the University of Saskatchewan Research Services Office. If you need further information about the study, please feel free to contact Lynn Jansen, RN, PhD (c) or Lynn's supervisors, Dr. Forbes or Dr. McWilliam. Thank you.

Yours sincerely,

---

Lynn Jansen RN, PhD (c)  
 School of Nursing  
 University of Western Ontario

Consent to Participate: I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. A copy of this consent form has been given to me for my records.

---

(Signature of Participant)

(Date)

---

(Signature of Researcher)

(Date)

1. On completion of the study, would you like a copy of the Executive Summary?

YES \_\_\_\_\_

NO  \_\_\_\_\_

2. I consent to the researcher contacting me regarding participation in a future research study.

YES  \_\_\_\_\_

NO \_\_\_\_\_

## Appendix C Interview Guide



Semi-structured interview guide (hermeneutic phenomenological approach to explore: what is the caregivers' experience with knowledge translation related to urinary incontinence?)

Introduction: Discussion may occur prior to the commencement of the interview (e.g. introductions).

Thank-you for participating in this interview. I would like to understand as much as possible about your experience with sharing knowledge and learning how to go about management of bladder control for the person you care for who has difficulty with control of their bladder.

1. I would like to understand your daily experience as a caregiver providing bladder control care. To start, could you tell me about the general health status of the person you care for. Do you have any specific issues or concerns in this regard?
2. Please tell me what it has been like to assist the person you care for with bladder control?

The following probing questions may be used:

- a. What is your role in providing bladder control care?
- b. What kind of bladder control care do you provide?  
Tell me about your experience with bladder control at:
  - c. different times of the day,
  - d. night time versus day time,
  - e. day to day or month to month,
  - f. with in bed care and/or caring for the person who is mobile.
3. I'd like you to think about some of the really significant experiences you've had with bladder control care? Probes will include:
  - a. How do you provide bladder control care?
  - b. Can you tell me about what works and what doesn't work for bladder control?
  - c. What are some of the facilitators and barriers of bladder control care that you have experienced?
  - d. Can you tell me about the involvement of others who may assist the person you care for with bladder control.

- e. Can you tell me about possible feelings of caregiver burden, frustration of control, even possibly feelings of failure, success and satisfaction/dissatisfaction?

Please feel free to add more information about the questions we have discussed throughout the interview. Now I would like to discuss with you your experience with information and learning about ways to assist the person you care for with bladder control problems.

4. Could you tell me about your experience with information and/or learning about bladder control:

Probes:

- a. Tell me about your experience with bladder control prior to being a caregiver.
- b. What did you need to know about bladder control care as a caregiver?
- c. What type of information sharing and/or education might you have participated in since you experienced caregiving? What was it like? What did you think about that?
- d. What were your expectations and goals related to bladder control knowledge sharing and/or education?
- e. What bladder control information was shared?
- f. What if anything did you learn from sharing this information?
- g. How did you obtain this information and/or learning about bladder control management?
- h. How did you use this information in bladder control care? (ask early and repeatedly until all sources are identified). What changes, if any have occurred following application of this information to bladder control management?

Additional Probes:

- i. Where did you share knowledge and learn about bladder control management?  
What did you think about that?
  - j. When did you share knowledge and learn about bladder control management?
  - k. Whom did you share knowledge and learn about bladder control with:
    - home care professionals and personal care/home care workers;
    - neighbors, friends, relatives;
    - support groups, self care efforts;
    - the person you care for who needs help with bladder control.
  - l. How were the above groups and individuals involved with your knowledge sharing and learning about bladder control?
5. What things were important for the above groups and/or individuals to consider on your behalf when you discussed and/or shared information and/or education about bladder control care?
  6. How did you feel about your experience of bladder control knowledge sharing and learning? How did you feel about your experience of bladder control knowledge sharing and learning with any of the individuals and/or groups you have identified above?

7. What would help you deal with bladder control care? Is there anything else you would like to share regarding your experience with bladder control care, and acquiring information, learning, and/or education about bladder control care? Do you have any questions about bladder control care that remain unanswered?
8. In an ideal world, what would your preparation for providing care for bladder control care be like?

Appendix D  
Letter of Introduction for Caregivers



The Process of Family Caregiver Knowledge Translation

Case Manager or Home Care Nurse will telephone and/or visit family caregivers using the information in this letter to obtain consent for release of the caregiver's name to the researcher.

The Five Hills Health Region is working with a Doctoral nursing student from the University of Western Ontario who is also a nursing professor at the University of Saskatchewan, College of Nursing, Regina site. The purpose of the research is to study the process and approaches of family caregivers' and clients' learning how to go about the management of in-home bladder control care with health care providers (i.e. nurses and home health care workers). The results of this study may help home care programs and other health care agencies to improve health services delivery for clients who need help with bladder control, and their family caregivers. You, as the family caregiver, are invited to take part in this study.

If you agree to take part, we will provide your name to the researcher, Lynn Jansen, a nurse, who is conducting the research study in partial fulfillment of a doctoral degree in nursing. Mrs. Jansen will phone you and arrange a visit to your home at a time convenient to you to ask you about your experience managing loss of bladder control in a family member. You will be asked to participate in a minimum of two interviews. Each interview will take about one to one and a half hours of your time. Your answers will be strictly private and confidential.

Can we provide your name to the researcher?

I consent to the release of my name to Mrs. Lynn Jansen, who is conducting a research study in partial fulfillment of a doctoral degree in nursing.

---

(Signature of Caregiver)

(Date)

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(Signature of Home Care Staff)

(Date)

Appendix E  
Letter of Introduction for Clients



The Process of Family Caregiver Knowledge Translation

Case Manager or Home Care Nurse will telephone and/or visit care recipients using the information in this letter to obtain consent for release of the care recipient's name to the researcher.

The Five Hills Health Region is working with a Doctoral nursing student from the University of Western Ontario who is also a nursing professor at the University of Saskatchewan, College of Nursing, Regina site. The purpose of the research is to study the process and approaches of family caregivers' and clients' learning how to go about the management of in-home bladder control care with health care providers (i.e. nurses and home health care workers). The results of this study may help home care programs and other health care agencies to improve health services delivery for clients who need help with bladder control, and their family caregivers. You, as a client of home care services, are invited to take part in this study.

If you agree to take part, you will be telephoned by the researcher, Lynn Jansen, a nurse, who is conducting the research study in partial fulfillment of a doctoral degree in nursing. Mrs. Jansen will arrange a visit to your home at a time convenient for you, to interview you about how you may have shared knowledge and learned how to go about bladder control care with health care providers and the family caregiver who assists you with bladder control. You will be asked to participate in a minimum of two interviews. Each interview will take about one to one and a half hours of your time. Your answers will be strictly private and confidential.

Can we provide your name to the researchers?

I consent to the release of my name to Mrs. Lynn Jansen, who is conducting a research study in partial fulfillment of a doctoral degree in nursing.

---

(Signature of Care Recipient)

(Date)

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(Signature of Home Care Staff)

(Date)

Appendix F  
Letter of Introduction for Health Care Providers



The Process of Family Caregiver Knowledge Translation

The Five Hills Health Region is working with a Doctoral nursing student from the University of Western Ontario who is also a nursing professor at the University of Saskatchewan, College of Nursing, Regina site. The purpose of the research is to study the process and approaches of family caregivers' and clients' learning how to go about the management of in-home bladder control care with health care providers (i.e. nurses and home health care workers). The results of this study may help home care programs and other health care agencies to improve health services delivery for clients who need help with bladder control, and their family caregivers. You, as a home care provider, are invited to take part in this study.

If you agree to take part, you will be telephoned by the researcher, Lynn Jansen, a nurse, who is conducting the research study in partial fulfillment of a doctoral degree in nursing. Mrs. Jansen will arrange a visit to your home or to a mutually agreed location at a time convenient for you. The purpose of the visit is to interview you about how teaching and learning about urinary incontinence may unfold among home care providers, clients and caregivers. You will be asked to participate in a minimum of two interviews. Each interview will take about one to one and a half hours of your time. Your answers will be strictly private and confidential.

Can the researcher phone you at your home care office number to discuss your participation in the research study?

I consent to a phone call at my place of work by Mrs. Lynn Jansen, who is conducting a research study in partial fulfillment of a doctoral degree in nursing.

---

**(Signature of Home Care Staff)**

**(Date)**



## Appendix G Caregiver Consent Form



### The Process of Caregiver Knowledge Translation

#### What This Study is About:

The Five Hills Health Region is working with a researcher who is an Assistant Professor of Nursing at the University of Saskatchewan, College of Nursing and a doctoral nursing candidate at the University of Western Ontario. This research is being conducted in partial fulfillment of the degree of doctor of philosophy in nursing. The nursing student would like to ask you to take part in interviews in your home. The interviews will be about your experience with sharing information and learning about being a caregiver of someone who has difficulty with bladder control. The results of this study may help home care programs and other health care agencies to improve health services delivery for clients with loss of bladder control and their family caregivers. As a caregiver, you are invited to take part in this study.

#### What Being in This Study Means for You:

Your participation in this study may help home care and other health care agencies to improve health services for clients who need help with bladder control. However you may not benefit personally from your participation. If you agree to take part, you will be telephoned by the researcher, who will arrange a minimum of two visits to your home at a time convenient to you. During the visits, you will be asked a series of questions during a tape-recorded interview about your experience of acquiring learning regarding being a caregiver of someone who has difficulty with control of their bladder. Each visit will take about 1 ½ hours of your time.

Questions you will be asked will focus on your experience of providing care for someone with bladder control difficulties and your experience with information and education about bladder control care. You may choose to not answer any of these questions. If you do answer them, your answers to these questions will be kept confidential. No names or identifying information will appear on the transcript that is created from the audiotape or within any research reports which may contain interview quotes from this study. A code number will be assigned to the transcript to ensure anonymity. Tape recordings and transcripts will be kept in a locked filing cabinet. Following completion of the study, the researcher may continue to review your interview information contained on the de-identified transcripts from this study. This process is known as secondary analysis and may be done to gain more understanding of the interview information obtained from your experience of acquiring learning about bladder control care. By consenting to participate in this study, you agree to the researcher doing

future secondary analysis with your interview data. Transcripts and audiotapes will be kept for a maximum period of seven years, at which time the audiotapes will be erased and the transcripts will be destroyed. None of this information will be put in any records of the care in the home of the person for whom you are a caregiver.

The researcher may wish to contact you in the future to participate in a new research study. You can indicate whether you wish to be contacted by the researcher for future research by checking a box at the end of this consent form. If you do wish to be contacted by the researcher your name and contact information will be maintained on a file locked in a filing cabinet separate from the de-identified interview transcript data obtained in this study. Your name and contact information will be maintained for a maximum period of seven years at which time your name and contact information will be destroyed.

#### Actions to Protect Your Rights:

Taking part in this study is voluntary. You may refuse to take part, refuse to answer any questions, or withdraw from the study at any time with no effect on your in-home services and care. If you decide to withdraw from the study it may not be possible to erase your tape-recorded interviews and destroy your data transcripts if your interview information has been de-identified. There is a risk that you may get tired or upset from answering these questions. If you do get tired, the interviewer will provide you with a break or stop the interview and come back to finish it at another time convenient to you. If you are upset, the researcher will provide a list of community resources to assist you and she will call your case manager with your permission to arrange any care you need to address the problem.

This letter is yours to keep. If you agree to take part in this study, you will be asked to sign a consent form. You will receive a copy of the consent form after it has been signed. Representatives of the University of Western Ontario Health Sciences Research Ethics Board or University of Saskatchewan Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

This study has been reviewed and approved by the University of Western Ontario Human Subject Research Ethics Board on August 17, 2010 and reviewed and approved by the University of Saskatchewan Behavioural Research Ethics Board on September 10, 2010. If you have any questions about the conduct of this study or your rights as a research subject, you may contact the Office of Research Ethics, The University of Western Ontario, or the University of Saskatchewan Research Services Office. If you need further information about the study, please feel free to contact Lynn Jansen, RN, PhD (c) or Lynn's supervisors, Dr. Forbes or Dr. McWilliam. Thank you.

Yours sincerely,

---

Lynn Jansen RN, PhD (c)  
School of Nursing  
University of Western Ontario

Consent to Participate: I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. A copy of this consent form has been given to me for my records.

---

(Signature of Participant)

(Date)

---

(Signature of Researcher)

(Date)

On completion of the study, would you like a copy of the Executive Summary?

YES

NO

I consent to the researcher contacting me regarding participation in a future research study.

YES

NO

## Appendix H Care Recipient Consent Form



### The Process of Caregiver Knowledge Translation

#### What This Study is About:

The Five Hills Health Region is working with a researcher who is an Assistant Professor of Nursing at the University of Saskatchewan College of Nursing and a doctoral nursing candidate at the University of Western Ontario. This research is being conducted in partial fulfillment of the degree of doctor of philosophy in nursing. The nursing student would like to ask you to participate in an interview in your home. This interview will be about how you may interact with, share knowledge, and learn about bladder control care with your caregiver (or someone who assists you with bladder control), and home care providers (such as professional nurses, home health care aides). Results may help home care programs and other health care agencies to improve health services delivery for clients with loss of bladder control and their caregivers. As a client of home care, you are invited to be one of the participants who will take part in this study.

#### What Being in This Study Means for You:

Your participation in this study may help home care and other health care agencies to improve health services for clients who need help with bladder control. However you may not benefit personally from your participation. If you agree to take part, you will be telephoned by the researcher, who will arrange two visits to your home at a time convenient to you. During the visits, you will be asked a series of questions during a tape-recorded interview about the process of how you have acquired information, education and learning regarding managing bladder control, and how you may share this information with your health care provider and family caregiver. Each visit will take about 1 ½ hours of your time. You may choose to not answer any of these questions. If you do answer them, your answers to these questions will be kept confidential. No names will appear on the transcript that is created from the audiotape. A code number will be assigned to the transcript to ensure anonymity. No names or identifying information will appear on the transcript that is created from the audiotape or within any research reports which are developed from this study. A code number will be assigned to the transcript to ensure anonymity. Tape recordings and transcripts will be kept in a locked filing cabinet. Following completion of the study, the researcher may continue to review your interview information contained on the de-identified transcripts from this study. This process is known as secondary analysis and may be done to gain more understanding of the interview information obtained from your experience of acquiring learning about bladder control care. By consenting to participate in this study, you agree to the researcher doing future secondary analysis with your interview data.

Transcripts and audiotapes will be kept for a maximum period of seven years, at which time the audiotapes will be erased and the transcripts will be destroyed. None of this information will be put in a home record for the care you receive in your home.

The researcher may wish to contact you in the future to participate in a new research study. You can indicate whether you wish to be contacted by the researcher for future research by checking a box at the end of this consent form. If you do wish to be contacted by the researcher your name and contact information will be maintained on a file locked in a filing cabinet separate from the de-identified interview transcript data obtained in this study. Your name and contact information will be maintained for a maximum period of seven years at which time your name and contact information will be destroyed.

Actions to Protect Your Rights:

Taking part in this study is voluntary. You may refuse to take part, refuse to answer any questions, or withdraw from the study at any time with no effect on your in-home services and care. There is a possibility that you may get tired or upset from answering these questions. If you do get tired, the interviewer will provide you with a break or stop the interview and come back to finish it at another time convenient to you. If you are upset, the researcher will provide a list of community resources to assist you, she will call your case manager with your permission to arrange any care you need to address the problem.

This letter is yours to keep. If you agree to take part in this study, you will be asked to sign a consent form. You will receive a copy of the consent form after it has been signed. Representatives of the University of Western Ontario Health Sciences Research Ethics Board or University of Saskatchewan Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

This study has been reviewed and approved by the University of Western Ontario Human Subject Research Ethics Board on August 17, 2010 and approved by the University of Saskatchewan Behavioural Research Ethics Board on September 17, 2010. If you have any questions about the conduct of this study or your rights as a research subject, you may contact the Office of Research Ethics, The University of Western Ontario or the University of Saskatchewan Research Services Office. If you need further information about the study, please feel free to contact Lynn Jansen, or Lynn's supervisor, Dr. McWilliam. Thank you.

Yours sincerely,

---

Lynn Jansen RN, PhD (c)  
School of Nursing  
University of Western Ontario

Consent to Participate: I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. A copy of this consent form has been given to me for my records.

---

(Signature of Participant)

(Date)

---

(Signature of Researcher)

(Date)

On completion of the study, would you like a copy of the Executive Summary?

YES

NO

I consent to the researcher contacting me regarding participation in a future research study.

YES

NO

## Appendix I Care Provider Consent Form



### The Process of Caregiver Knowledge Translation

#### What This Study is About:

The Five Hills Health Region is working with a researcher who is an Assistant Professor of Nursing at the University of Saskatchewan College of Nursing and a doctoral nursing candidate at the University of Western Ontario. This research is being conducted in partial fulfillment of the degree of doctor of philosophy in nursing. The nursing student would like to ask you to participate in an interview in your home or setting of your choice. This interview will be about how teaching and learning about urinary incontinence unfolds among home care providers, clients and caregivers. Results may help home care programs and other health care agencies to improve health services delivery for clients and their caregivers. As a home care provider, you are invited to be one of the participants who will take part in this study.

#### What Being in This Study Means for You:

Your participation in this study may help home care and other health care agencies to improve health services for clients who need help with bladder control. However you may not benefit personally from your participation. If you agree to take part, you will be telephoned by the researcher, who will arrange two visits to your home or an interview setting of your choice. During the visits, you will be asked a series of questions in a tape-recorded interview about how you share knowledge and information with clients who experience difficulty with bladder control, and their in-home caregivers. Each visit will take about 1 ½ hours of your time.

Questions will ask about your experience and approaches with sharing information and education about bladder control care with the client who experiences difficulty with bladder control and their family caregiver. You may choose to not answer any of these questions. If you do answer them, your answers to these questions will be kept confidential. No names will appear on the transcript that is created from the audiotape. A code number will be assigned to the transcript to ensure anonymity. Tape recordings and transcripts will be kept in a locked filing cabinet. Following completion of the study, the researcher may continue to review your interview information contained on the de-identified transcripts from this study. This process is known as secondary analysis and may be done to gain more understanding of the interview information obtained from your experience of acquiring learning about bladder control care. By consenting to participate in this study, you agree to the researcher doing future secondary analysis with

your interview data. Transcripts and audiotapes will be kept for a maximum period of seven years at which time, the audiotapes will be erased and the transcripts will be destroyed.

The researcher may wish to contact you in the future to participate in a new research study. You can indicate whether you wish to be contacted by the researcher for future research by checking a box at the end of this consent form. If you do wish to be contacted by the researcher your name and contact information will be maintained on a file locked in a filing cabinet separate from the de-identified interview transcript data obtained in this study. Your name and contact information will be maintained for a maximum period of seven years at which time your name and contact information will be destroyed.

Actions to Protect Your Rights:

Taking part in this study is voluntary. You may refuse to take part, refuse to answer any questions, or withdraw from the study at any time with no effect on your home care position. This letter is yours to keep. If you agree to take part in this study, you will be asked to sign a consent form. You will receive a copy of the consent form after it has been signed. Representatives of the University of Western Ontario Health Sciences Research Ethics Board or University of Saskatchewan Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

This study has been reviewed and approved by the University of Western Ontario Human Subject Research Ethics Board on August 17, 2010 and approved by the University of Saskatchewan Behavioural Research Ethics Board on September 17, 2010. If you have any questions about the conduct of this study or your rights as a research subject, you may contact the Director, Office of Research Ethics, The University of Western Ontario, or the University of Saskatchewan Research Services Office. If you need further information about the study, please feel free to contact Lynn Jansen, RN, PhD (c) or Lynn's supervisors, Dr. Forbes or Dr. McWilliam. Thank you.

Yours sincerely,

---

Lynn Jansen RN, PhD (c)  
School of Nursing  
University of Western Ontario



Consent to Participate: I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction. A copy of this consent form has been given to me for my records.

---

(Signature of Participant)

(Date)

---

(Signature of Researcher)

(Date)

On completion of the study, would you like a copy of the Executive Summary?

YES

NO

I consent to the researcher contacting me regarding participation in a future research study.

YES

NO

Appendix J  
Semi-structured Interview Guide for Caregiver



Semi-structured interview guide for caregiver (grounded theory approach to study the process of how providers, caregivers and clients interact to achieve UI KT within the context of in-home care).

Thank-you for agreeing to participate in this interview.

Today I would like to discuss some questions with you so that I can understand as much as possible about how you came about learning and sharing knowledge about the management of bladder control for the person you are a caregiver for. To start, could you tell me about the general health status of the person you care for. Do you have any specific issues or concerns in this regard?

1. Could you tell me what it has been like to assist the person you care for with bladder control?

Probes:

- a. What is your role in providing bladder control care?
  - b. How do you manage bladder control for the person you care for?
  - c. Could you tell me how you came about doing what you do in managing bladder control?
  - d. Tell me about your experience with bladder care during:
    - different times of the day,
    - night time versus day time,
    - day to day or month to month,
    - with in bed care and/or caring for the person who is mobile.
2. I'd like you to think about some of the really significant experiences you've had with bladder control care? Can you think of something that stands out in your mind?

Probes:

- a. What are some of the facilitators and barriers of bladder control care that you have experienced?
- b. What works and doesn't work for bladder control care?
- c. Can you tell me about the involvement of others in bladder control care?
- d. Can you tell me about possible feelings of frustration of control, even possibly feelings of failure, success and satisfaction/dissatisfaction?

Please feel free to add more information about the questions we have discussed throughout the interview. Now I would like to discuss with you your experience with information, learning, and education about ways to assist the person you care for with bladder control problems.

3. Could you tell me how you came about any information, education, learning, and knowledge sharing through interacting with others to go about providing bladder control care? (ask early and repeatedly until all sources are identified).

Probes:

- a. What was it like? What did you think about that?
- b. What were your expectations and goals about learning about bladder control care?
- c. What education, learning, information and knowledge sharing did you obtain?
- d. How has your experience before you got involved with bladder control care entered into how you've gone about bladder control education/knowledge sharing?

4. Could you tell me how (if at all) sharing knowledge about bladder control management has occurred for you?

Probes:

- a. What were your expectations about sharing knowledge about bladder control?
- b. What things were important to consider on your behalf when you shared information and/or education about bladder control care with others?
- c. How did you connect with others to share knowledge?
- d. How did you obtain learning and information through sharing knowledge?
- e. How did you use this shared knowledge in bladder control care?
- f. What was this experience like? What did you think about it then?
- g. Where did you learn about bladder control care through sharing knowledge?
- h. When did you learn about bladder control care through sharing knowledge?
- i. Whom if anyone did you learn about bladder control from and whom if anyone entered into your decisions/actions regarding sharing knowledge about bladder care and application of this knowledge sharing for bladder control?
  - home care professionals and personal care/home care workers;
  - neighbors, friends, relatives;
  - support groups, self care efforts.

5. How did you feel about your experience with sharing knowledge/information about bladder control knowledge/information? How did you feel about your knowledge sharing experience that may have occurred with care providers? Neighbors, friends, relatives? Support groups, self care efforts?

6. As you look back on your experience with knowledge sharing about bladder control and learning about bladder control, is there anything that stands out in your mind? Could you describe this? How did it happen? How did you respond?
7. What was good about the learning/knowledge sharing processes you have described? What was not so good about the learning/knowledge sharing processes you have described?  
Probes:
  - a. What has been helpful? Not so helpful?
  - b. Where have these things been helpful/not so helpful?
  - c. Who has been most helpful to you during this time? How has he/she been helpful?
  - d. Who has not been helpful to you during this time? How has he/she not been helpful?
  - e. Has any organization been helpful/not helpful? How did this organization help/not help?
8. How if at all, have your actions and interactions about bladder control care changed since you participated in learning, sharing knowledge or talking about UI care with providers, clients? Others?  
  
Probe:  
How do these changes relate to learning/not learning about bladder control management?  
Tell me about how your views about how you've learned/not been able to learn about bladder control management?
9. Could you describe the most important lessons you have learned through the processes you have told me about?
10. What do you think would be the best ways to learn about bladder control? How did you discover or come up with these approaches?
11. Is there anything else I should know to better understand how learning about knowledge and information sharing about bladder control has occurred for you?
12. Is there anything you would like to ask me?

## Appendix K Semi-structured Interview Guide for Care Recipient



Semi-structured interview guide for care recipient (Grounded Theory approach to explore the process of how providers, caregivers and clients interact to achieve UI KT within the context of in-home care).

Discussion may occur prior to the commencement of the interview (e.g. introductions).

Thank-you for participating in this interview. Today, I would to discuss some questions with you so that I can understand as much as possible about your experience with the process of sharing and learning knowledge about the management of bladder control.

Initial Open-ended questions:

1. Could you tell me about your general health status? Any specific concerns?
2. Could you tell me what it has been like to have difficulty with bladder control?  
Probe:
  - a. Tell me about how you go about a typical day/home care visit in managing bladder control?
  - b. Tell me about how you came to do what you do in managing bladder control?
  - c. What has been your experience day to day or month to month?
  - d. What has been your experience in managing bladder control while you are in bed and/or up and moving around?
3. I'd like you to think about some of the really significant experiences you've had with managing bladder control. Can you think of something that stands out in your mind?

Probe:

- a. Can you tell me about what works and what does not work for bladder control?
- b. Can you tell me about the involvement of others in bladder control care?
- c. Can you tell me about possible feelings of frustration of control, even possibly feelings of failure, success and satisfaction/dissatisfaction?

Please feel free to add any additional information or thoughts you may have about your experience in managing bladder control throughout our discussion.

I would like to progress to discussion about:

4. Could you tell me how you came about any information, education, learning, and knowledge sharing through interacting with others to go about providing bladder control care? (ask early and repeatedly until all sources are identified).
5.
 

Probes:

  - a. What was it like? What did you think about then?
  - b. What were your expectations and goals related to sharing knowledge about bladder control management?
  - c. What information was shared? What was your role in sharing bladder control information? How was this information shared?
  - d. How did you connect with others to share knowledge about bladder control care?
  - e. How has your experience before you got involved with bladder control care entered into how you've gone about bladder control education/knowledge sharing?
  - f. How did you use this shared knowledge in managing your bladder control?
  - g. Where was bladder control/knowledge shared?
  - h. When was bladder control/knowledge shared?
  - i. Who was involved with sharing this information? Your caregiver, other home care/health care professionals, personal care/home care workers, support groups and self care efforts?
  - j. Who if anyone entered into or influenced your actions regarding knowledge sharing for bladder control management and application of this knowledge for bladder control?
  - k. Tell me about how he/she and/or they may have influenced and/or interacted with you?
  - l. How did you feel about the knowledge sharing process?
6. What was good about the learning/knowledge sharing processes you have described? What was not so good about the learning/knowledge sharing processes you have described?
 

Probes:

  - a. What has been helpful? Not so helpful?
  - b. Where have these things been helpful/not so helpful?
  - c. Who has been most helpful to you during this time? How has he/she been helpful?
  - d. Who has not been helpful to you during this time? How has he/she not been helpful?
  - e. Has any organization been helpful/not helpful? How did this organization help/not help?
7. How if at all, have your actions and interactions about bladder control care changed since you participated in learning, sharing knowledge or talking about UI care with your caregiver, home care provider? Others?

Probe:

- a. How do these changes relate to learning/not learning about bladder control management?
  - b. Tell me about how your views about how you've learned/not been able to learn about bladder control management?
8. Could you describe the most important lessons you have learned through the processes you have told me about?
  9. What do you think would be the best ways to learn/share knowledge about bladder control? How did you discover or come up with these approaches?
  10. Is there anything else you I should know to better understand how learning about knowledge and information sharing about bladder control has occurred for you?
  11. Is there anything you would like to ask?

Appendix L  
Semi-Structured Interview Guide for Care Provider



Semi-structured interview guide for care provider (Grounded Theory approach to explore the process of how providers, caregivers and clients interact to achieve UI KT within the context of in-home care).

Thank-you for participating in this interview. Today, I would like to discuss some questions with you so that I can understand as much as possible about how teaching and learning about urinary incontinence unfolds among home care providers, care recipients, and caregivers.

1. To start, I would like to understand your daily experience as an in-home care provider involved in providing care to someone who experiences loss of bladder control. Tell me what it has been like.

Probes:

Can you tell me about your experience with clients, and their caregivers with the following characteristics:

- a. Male and female in-home clients,
  - b. Socio-economic status,
  - c. Rural/urban home care setting
  - d. Care required at different times of the day
  - e. Care required at night time versus day time
  - f. Care required day to day or month to month
  - g. With in bed care and/or caring for the person who is mobile.
2. I'd like you to think about some of the really significant experiences you've had with bladder control care? Probes will include:
    - a. What kind of bladder control care do you provide?
    - b. How do you provide bladder control care?
    - c. What are some of the facilitators and barriers of in-home bladder control care that you have experienced as a home care provider?
    - d. Can you tell me about the involvement of others within in-home bladder control care?
    - e. Can you tell me about possible feelings of frustration of control, even possibly feelings of failure, success and satisfaction/dissatisfaction?



Please feel free to add additional information regarding the questions we have discussed throughout the interview. Now that we have discussed your experience with providing UI care, I would like to discuss with you your experience with the process of sharing information and education about ways to assist the person you care for and/or caregiver with bladder control.

3. Could you tell me about your experience with sharing information, knowledge and/or education about bladder control through interacting with others:
  - a. What was this experience like?
  - b. What was your role in providing information on bladder control care?
  - c. What did you need to know about bladder control care?
  - d. What type of information was this that you needed to know and how did you use it in bladder control care? (ask early and repeatedly until all sources are identified).
  - e. What were your expectations and goals related to bladder control knowledge sharing?
  - f. What information/knowledge was shared?
  - g. What things were important for the care giver and/or client to consider when you discussed information and/or education about bladder control care?
  - h. How did you connect with caregivers and clients to share knowledge and information about bladder control care?
  - i. How prepared do you feel in providing care/offering guidance on bladder control?
  
4. How did you interact and/or share information and/or knowledge with the caregiver and/or care recipient?
  - a. How did you use and apply the knowledge you received from other home care providers, caregivers, and/or clients?
  - b. Where was this knowledge shared?
  - c. When was this knowledge shared?
  - d. What did you think about that?
  - e. How do you feel about that?
  
5. From whom else/where have you engaged with in sharing information and/or education about bladder control:
  - a. Home care professionals and other colleagues? Personal care/home care workers?
  - b. Inservice sessions
  - c. Basic training
  - d. Online resources etc
  - e. Bladder management support groups
  - f. Anyone else?
  
6. Who if anyone entered into or influenced your actions regarding sharing knowledge for bladder control management and application of knowledge for bladder control?

Probe:

Tell me about how she/he and/or they influenced entered into your actions for knowledge sharing?

7. What was good about the knowledge sharing processes you have described? What was not so good about the knowledge sharing processes you have described?

Probe:

- a. What has been helpful? Not so helpful?
  - b. Where have these things been helpful/not so helpful?
  - c. Who has been most helpful to you during this time? How have he/she and/or they been helpful?
  - d. Who has not been helpful to you during this time? How have he/she and/or they not been helpful?
  - e. Has any organization been helpful/not helpful? How did this organization help/not help?
8. What if anything do you know now that you didn't know prior to engaging in sharing knowledge for bladder control?
  9. How if at all, have your actions and interactions about bladder control care changed since you participated in sharing knowledge with caregivers and care recipients? Others?
  10. Could you describe the most important lessons you have learned through the processes you have told me about?
  11. What do you think would be the best ways to share knowledge about bladder control? How did you discover or come up with these approaches?
  12. Is there anything else you I should know to better understand learning about knowledge and information sharing about bladder control care?
  13. Is there anything you would like to ask me?

Appendix M  
Separate Guide for Observation



Separate guide for observation if the researcher is observing social interactions and evidence of tacit knowledge:

If I am observing social interactions and evidence of tacit knowledge, I will ask:

What is it that they are doing? For example, "I just saw you do this –

What are your needs at this moment?

What are your intentions at this moment?

What are your expectations at this moment?

What are your understandings at this moment? How is this occurring for you?

How do you feel after the fact, what were you consciously thinking about?

Appendix N  
Caregivers Demographic Form



What is your relationship to the family member or friend for whom you are caring:  
(please check *one*)

- \* wife/common law partner
- \* husband/common law partner
- \* daughter
- \* son
- \* sister
- \* brother
- \* sister-in-law
- \* brother-in-law
- \* grand-daughter
- \* grandson
- \* niece
- \* nephew
- \* friend
- \* neighbour
- \* Other (please specify): \_\_\_\_\_

2. What is your age? \_\_\_\_\_ years old

3. What is your gender?      \* Female                      \* Male

4. What is your marital status? (please check one)

- \* married
- \* separated
- \* common-law relationship
- \* divorced
- \* widowed
- \* single (never married)

5. Which one of the following categories best describes you at present? (check *one*)

- \* Employed full-time
- \* Retired
- \* Employed part-time
- \* Unemployed/on strike
- \* Full-time homemaker
- \* Unable to work due to illness or disability
- \* Other (please specify): \_\_\_\_\_

6. What type of community do you live in?

- O Urban (15,000 people or more)
- O Rural (less than 15,000 people)

8. What is the age of your family member or friend for whom you are caring?  
\_\_\_\_\_ years old

9. What is the gender of your family member or friend for whom you are caring?

- \* Male
- \* Female

10. How long have you been providing?  
 (a) in-home care for the family member?  
 (b) bladder control care?

11. Where is your family member or friend living currently and how long has he or she been living there? (complete one line)

Your family member or friend is currently living .... How long has he/she lived there?

- \* in his or he own home or apartment ..... \_\_\_\_ years
- \* in your home ..... \_\_\_\_ years
- \* in another family member's home ..... \_\_\_\_ years
- \* in a retirement home/village..... \_\_\_\_ years
- \* in a senior's apartment ..... \_\_\_\_ years
- \* in a nursing home/home for the aged ..... \_\_\_\_ years
- \* in a hospital/chronic care facility ..... \_\_\_\_ years
- Other (please specify): ..... \_\_\_\_ years

12. Do you live with the family member who is the care recipient for bladder control care?

Yes\_\_\_\_\_

No\_\_\_\_\_

Appendix O  
Care Recipients Demographic Form



What is your relationship to the family member or friend who assists you with bladder control care? (please check *one*)

- |                                 |                              |
|---------------------------------|------------------------------|
| * wife/common law partner       | * husband/common law partner |
| * daughter                      | * son                        |
| * sister                        | * brother                    |
| * sister-in-law                 | * brother-in-law             |
| * grand-daughter                | * grandson                   |
| * niece                         | * nephew                     |
| * friend                        | * neighbour                  |
| * Other (please specify): _____ |                              |

2. What is your age? \_\_\_\_\_ years old

3. What is your gender?      \* Female                      \* Male

4. What is your marital status? (please check one)

- |                           |                          |
|---------------------------|--------------------------|
| * married                 | * separated              |
| * common-law relationship | * divorced               |
| * widowed                 | * single (never married) |

5. Which one of the following categories best describes you at present? (check *one*)

- |                                 |   |
|---------------------------------|---|
| * Employed full-time            | * Retired                                     |
| * Employed part-time            | * Unemployed/on strike                        |
| * Full-time homemaker           | * Unable to work due to illness or disability |
| * Other (please specify): _____ |   |

6. What type of community do you live in?

- |                             |                             |
|-----------------------------|-----------------------------|
| <input type="radio"/> Urban | <input type="radio"/> Rural |
| (15,000 people or more)     | (less than 15,000 people)   |

7. How long have you received home care?

8. How long have you experienced difficulty with bladder control?

9. How long have you received assistance with bladder control care from your caregiver?

Appendix P  
Care Providers Demographic Form



1. Are you a: (check *one*)
  - \* Registered Nurse:
  - \* Home Care Aide:
  - \* Social Worker:
  - \* Therapist (OT, Physical therapist, Respiratory therapist):
  - \* Other (please specify): \_\_\_\_\_:
  
2. Is this position primarily:
  - \* management/administrative:
  - \* direct client care:
  - \* case manager:
  
3. Where do you work?
  - \* Home care program:
  - \* Other (please specify): \_\_\_\_\_ :
  
4. Do you consider your workplace
  - \* rural?
  - \* urban?
  
5. What is the population within the geographical area that you cover in your work?
  
6. Approximately how many clients with urinary incontinence did you see in the last month?
  
7. Approximately what percentage of your current clients have urinary incontinence?
  
8. What is your age? \_\_\_\_\_ years old
  
9. What is your gender?
  - \* Female
  - \* Male

## Appendix Q Ethics Certificates



### Office of Research Ethics

The University of Western Ontario  
Room 4180 Support Services Building, London, ON, Canada N6A 5C1  
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca  
Website: www.uwo.ca/research/ethics

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AUG 17 2009

University of Saskatchewan  
Research Ethics Office

### Use of Human Subjects - Ethics Approval Notice

**Principal Investigator:** Dr. D.A. Forbes

**Review Number:** 16065E

**Revision Number:** 1

**Review Date:** July 02, 2009

**Review Level:** Expedited

**Protocol Title:** The Process of Caregiver Knowledge Translation

**Department and Institution:** Nursing, University of Western Ontario

**Sponsor:** SSHRC-SOCIAL SCIENCE HUMANITIES RESEARCH COUNCIL

**Ethics Approval Date:** July 02, 2009

**Expiry Date:** August 31, 2010

**Documents Reviewed and Approved:** Revised study end date.

**Documents Received for Information:**

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

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

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

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

Chair of HSREB: Dr. Joseph Gilbert

Ethics Officer to Contact for Further Information			
<input type="checkbox"/> Janice Sutherland (jsutherl@uwo.ca)	<input type="checkbox"/> Elizabeth Wambolt (ewambolt@uwo.ca)	<input checked="" type="checkbox"/> Grace Kelly (grace.kelly@uwo.ca)	<input type="checkbox"/> Denise Grafton (dgrafton@uwo.ca)

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

cc: ORE File





UNIVERSITY OF  
SASKATCHEWAN

Behavioural Research Ethics Board (Beh-REB)

**Certificate of Approval**

PRINCIPAL INVESTIGATOR  
Dorothy A. Forbes (UWO)

DEPARTMENT  
Nursing

BEH#  
09-122

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED

University of Saskatchewan

University of Western Ontario

CO-INVESTIGATOR(S)  
Carol McWilliam (UWO)

STUDENT RESEARCHERS  
Lynn Jansen

SPONSOR  
SOCIAL SCIENCES AND HUMANITIES RESEARCH COUNCIL OF CANADA (SSHRC)

TITLE  
The Process of Caregiver Knowledge Translation

ORIGINAL REVIEW DATE  
19-May-2009

APPROVAL ON  
25-May-2009

APPROVAL OF:  
Ethics Application  
Consent Protocol

EXPIRY DATE:  
24-May-2010

Expedited Review

**CERTIFICATION**

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

**ONGOING REVIEW REQUIREMENTS**

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: [http://www.usask.ca/research/ethics\\_review](http://www.usask.ca/research/ethics_review)

Please send all correspondence to:

Research Ethics Office  
University of Saskatchewan  
Box 5000 RPO University, 1602-110 Gymnasium Place  
Saskatoon SK S7N 4J8



## Office of Research Ethics

The University of Western Ontario  
 Room 4180 Support Services Building, London, ON, Canada N6A 5C1  
 Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca  
 Website: www.uwo.ca/research/ethics

### Use of Human Subjects - Ethics Approval Notice

**Principal Investigator:** Dr. C. McWilliam

**Review Number:** 17276E

**Review Date:** July 21, 2010

**Review Level:** Expedited

**Approved Local # of Participants:** 40

**Protocol Title:** The Process of caregiver knowledge translation

**Department and Institution:** Nursing, University of Western Ontario

**Sponsor:**

**Ethics Approval Date:** August 17, 2010

**Expiry Date:** October 31, 2011

**Documents Reviewed and Approved:** UWO Protocol, Letter of Information and Consent (Caregiver - July 23, 2010), Letter of Information and Consent (Client - July 23, 2010), Letter of Information and Consent (Health Care Provider - July 23, 2010), Telephone Script (Caregiver), Telephone Script (Home Care Client), Telephone Script (Home Care Provider).

#### Documents Received for Information:

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

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

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

- changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- all adverse and unexpected experiences or events that are both serious and unexpected;
- new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

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

Chair of HSREB: Dr. Joseph Gilbert  
 FDA Ref. #: IRB 0000940

#### Ethics Officer to Contact for Further Information

Janice Sutherland  
 (jsuther1@uwo.ca)

Elizabeth Wambolt  
 (ewambolt@uwo.ca)

Grace Kelly  
 (grace.kelly@uwo.ca)

Denise Grafton  
 (dgrafton@uwo.ca)

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

cc: ORE File



**UNIVERSITY OF  
SASKATCHEWAN**

Behavioural Research Ethics Board (Beh-REB)

***Certificate of Approval***

PRINCIPAL INVESTIGATOR  
Lynn Jansen

DEPARTMENT  
Nursing

BEH#  
10-215

SUB-INVESTIGATOR(S)  
Carol McWilliam

SPONSOR  
UNIVERSITY OF WESTERN ONTARIO

TITLE  
The Process of caregiver knowledge translation

ORIGINAL REVIEW DATE  
22-Aug-2010

APPROVAL ON  
10-Sep-2010

APPROVAL OF  
Ethics Application  
Consent Protocol

EXPIRY DATE  
10-Sep-2011

Full Board Meeting

Date of Full Board Meeting:

Delegated Review

Expedited Review:

**CERTIFICATION**

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

**ONGOING REVIEW REQUIREMENTS**

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Please send all correspondence to:

Research Ethics Office  
University of Saskatchewan  
Box 5000 RPO University, 1602-110 Gymnasium Place  
Saskatoon SK S7N 4J8

Appendix R  
Supporting Data for Study One and Study Two

<b>Supporting Interview Data from Study One Used to Refine Themes and Sub-themes</b>	
<b>Caregivers' Experience of KT: Working Together/Not Working Together</b>	
<b>Home Care Contextual Facilitators and Barriers (Themes) and Sub-themes of:</b>	
Continuity/Discontinuity of Care Provider, Consistency/Inconsistency in Care Approach, Time for/Inadequate time for Developing Working Relationship	
<b>Sub-Themes</b>	<b>Supporting Interview Data</b>
<b>KT Facilitator: Continuity of Home Care Providers</b>	<p>You [care provider] have to be the same person to be familiar with the situation [caregiver's and care recipient's situation regarding UI concerns] and what you are talking about [care provider sharing knowledge and approaches to facilitate UI management/care]... I [caregiver] wanted to meet with the same person [care provider] as well so that when we were with grandma [care recipient] each of us [care provider, caregiver, and care recipient] knew what each other knew [about care recipient's UI care and education issues].</p> <p>There was one gentleman who would come all of the time if I needed him – all I had to do was give him a call. He was a care worker who came in twice a week. He could work with me to show me [caregiver] how to move my husband [care recipient] so that I could wash him [provide UI care].</p> <p>You get to know a lot about someone because you keep going into someone's home.</p>
<b>KT Barrier: Discontinuity of Home Care Providers</b>	<p>If they [home care agency] send somebody [care provider] different to do something [in-home care], they [home care providers] should know what they are doing. I had never seen them before. They would come in and say 'my name is such and such' and right away ask me what they [care provider] were supposed to do... "How was I to know what they were supposed to do!" It would have been easier to do it [in-home care] myself... I do realize that home care cannot always send the same people</p>

<p><b>KT Barrier (continued from previous page): Discontinuity of Home Care Providers</b></p>	<p>[care providers] but there must be something we can do [to provide more continuity of care providers].</p> <p>It would have been devastating to start [with a different care provider] all over again. All that mattered to us [caregiver and care recipient] were the people [care providers] who were looking after him and showing me what to do [to assist with UI care].</p> <p>One new person [care provider] came in and asked him [care recipient] dozens of questions – she was taking lots of notes. I [family caregiver] had to walk away because it was so funny. I came back when she was done and told her that he hadn't answered one of those questions correctly (re. age and place of former employment).</p>
<p><b>KT Facilitator: Consistency of Care Provider's approach</b></p>	<p>If you [caregiver and care provider] are dealing with an older person, don't change anything. Be consistent with what you are doing and keep the same people [care providers] involved until you get somewhere [with plans for in-home UI care]... We [caregiver and care provider] could <i>relate</i> [work together] with grandma [consistent approach and communication with addressing UI care issues with mother-in-law].</p> <p>But then if it was a real bath day, I would have him up and ready for breakfast and then they [regular care providers] would come to do the full bath. I knew when everything was going to happen... Everything was on a schedule – it was just routine for me.</p>
<p><b>KT Barrier: Inconsistency of Care Providers' approach</b></p>	<p>We were having all kinds of trouble. One [care provider] wanted to do it [bedsore and UI care] this way and one wanted to do it that way.</p>
<p><b>KT Facilitator: Time for developing working relationship</b></p>	<p>As you [caregiver] work it through [learn in-home and UI care together with care recipient and care provider] you ease over time into what needs to be done and how you go about it...Time is important to consider what has to be done [learning how to provide UI care]. If you don't agree right away [with UI learning and teaching approach] ...just think about it and come back to it after some thought.</p>

<p><b>KT Barrier: Inadequate time for developing working relationship</b></p>	<p>If someone [care provider] is coming in and in a rush – then we [caregivers] can't trust them. So you [care provider] want to take the time so I [caregiver] can trust you and you can have my trust. That would be one way to start by home 'caring'!</p>
<p align="center"><b>Personal Contextual Facilitators and Barriers (Themes) and Sub-themes arising from internal personal attributes</b></p>	
<p><b>Personal Contextual Themes and Sub-themes:</b> Respect/expectations, sensitivity/lack of sensitivity, patience/lack of patience, self-expectations/caregiver inability to articulate knowledge needs, authoritative stance</p>	<p align="center"><b>Supporting Interview Data</b></p>
<p><b>KT Facilitator:</b> <b>Respect for other</b></p>	<p>I [caregiver] feel that they [providers] have to learn that, "This is the way they [care recipients] are"...They [care providers] have to...be kind and respectful to them [when they work with care recipients] – this is the way they have to be if they want to get a response from them [care recipients]. If they can't get a response from them they will not be able to connect.</p>
<p><b>KT Barrier: Expectations of other</b></p>	<p>I [caregiver] am expecting them [care providers] to be a certain way because they are home care providers. They are expecting me [caregiver] to be a certain way because they are here to help me or however, we are thinking about each other. So we all have these 'expectations'. It's like we have a whole list of things to expect when we go into a home. We need to shut off this list of expectations, we need to be more basic.</p>
<p><b>KT Facilitators: Sensitivity toward other</b></p>	<p>We [caregiver and care provider] need to be sensitive to each other and appreciate each other for who we are and how we are with one another.</p>
<p><b>KT Barrier: Lack of Sensitivity to other</b></p>	<p>Some of them [care providers],... just sort of did the job without feeling [any sensitivity] for his [care recipient] needs.</p>
<p><b>KT Facilitators: Patience with each other</b></p>	<p>It [caregiver learning] was the patience they [care provider] had and taught me [caregiver] – just keep at it and it will eventually happen [caregiver will enact 'patience' when working with care recipient].</p>

<b>Personal Contextual Sub-themes:</b>	<b>Supporting Interview Data</b>
<b>KT Barrier: Lack of Patience</b>	<p>At the end just before he [care recipient] went into long term care, my patience was really thin. When a new person [care provider] came in, I just couldn't stay [in the room] with them [care provider and caregiver] to share all of his care information. She asked him [care recipient] dozens of questions. She was taking lots of notes...But [when caregiver returned], he hadn't answered one of those questions correctly.</p> <p>I am learning more from those [care providers] who understand the 'baggage' [emotions associated with care provider] and the way I react to them [angrily when I don't agree with them] than from the providers who react to me... The ones who are patient... They help me realize that I have to stop being like that ... I need to get a grip and count to 10 [to work with others].</p>
<b>KT Facilitator: Self-expectations</b>	<p>My job as a caregiver is to ensure that her [care recipient] needs are met and that she is comfortable so that is my job. If they [care providers] don't do things so that she is comfortable, I can't just walk away and say to mom, "That's the way it is!" I have to learn how to say it better [communicate to care providers how care is to be carried out] so that we can work with them.</p>
<b>KT barrier: Caregiver inability to articulate knowledge needs</b>	<p>Most of the time I almost never said anything, I don't know how. I just knew that they [care providers] looked at me as if to say, "Oh what do you want to know? I didn't know what I wanted to know. I just wanted some help, and if I had known what I wanted then I could have gone and done it". I felt like they [care providers] didn't understand [what I needed to know]... I [caregiver] mean it [inability to articulate her knowledge about care recipient's health condition] was my fault too, because I didn't know how to tell them [care providers].</p> <p>But when I needed someone to talk to [to ask for care information], I didn't tell anybody...I am a very private person – always have been</p>
<b>KT Barrier: Authoritative Stance</b>	<p>I think it would be helpful if they were listening to me without making me feel that ... they were the boss sort of thing, and that I was to listen to what they were saying and don't ask questions. That's the way I felt.</p>



<b>Working Together/Not Working Together</b>	
<b>Sub-themes</b>	
<b>Compromising/not compromising; Appreciating/not appreciating; Understanding/not understanding; Encouraging knowledge seeking/impeding knowledge seeking; Listening/not listening; Trusting/Not Trusting</b>	
<b>Sub-themes</b>	<b>Supporting Interview Data</b>
<b>One excerpt representing all of the processes of: Compromising, Appreciating, Understanding.</b>	<p>You just get along with people – [1.] <b>compromise</b> – [it is] not always your ideas what we do. The key is to [2.] <b>appreciate</b> what the other is doing – [3.] <b>understand</b> [the other’s perspective]. Then you can talk and do anything together. You can get so you don’t have to talk to each other – you just know what the other person [in-home caregiver] would do. It becomes automatic. Your heart and mind are working together. You are reading things you don’t even know you are reading.</p>
<b>Compromising</b>	<p>You just get along with people –<b>compromise</b> – it is not always your ideas what we do... We [caregivers] should always be open to change to someone else’s [care provider and care recipient] idea...They are a communicator and they want to be heard...We need to listen and be open to the ideas of others.</p> <p>You can’t force anybody into anything – you have to go along with them [care recipient] and change them [support options for UI care and KT] so that things get done that need to be done.</p>
<b>Not compromising</b>	<p>I [caregiver] said to the nurse ... if you would teach me how to change the dressing... I would teach everyone [home care providers] how to do the dressing the way it was written in the home care book. It was really frustrating to me that everyone [care providers] had their own way of doing it [no-one could agree on how to follow the care plan in a consistent way]. Therefore, I just backed off [did not try to teach the care providers any more] so we were not...working together.</p>
<b>Appreciating</b>	<p>The key is to <b>appreciate</b> what the other is doing.</p> <p>It’s not about coming into my house to please me. It’s like a mirror... I [caregiver] know you appreciate what I do as a caregiver and I appreciate you as the care provider...It mirrors back and it is like an exchange.</p>



	<p>You go away and I go away and everyone is happy – I feel good about myself and you feel good about yourself because you helped me to learn. You are doing your job.</p>
<b>Not appreciating</b>	<p>I [caregiver] feel like some of them [care providers] just don't appreciate what we [caregiver] know...like how he [care recipient] is thinking and communicating so that we [caregiver and care recipient] can work [together] with him.</p> <p>“It was hard to follow what they[providers] were trying to teach me.... They did not appreciate that I knew what worked.</p>
<b>Understanding</b>	<p><b>Understand</b> [the other's perspective] - then you [caregiver/care recipient dyad and care provider] can talk and do anything together. You [caregiver/care provider] can get so you don't have to talk to each other – you just know what the other person would do. It becomes automatic.</p> <p>I [caregiver] knew what was coming because of what he [care provider] shared with me. It prepared me for each situation and understanding how the disease was progressing...It was helpful to know that it [UI] was occurring because of the disease [dementia]...He told me as much as he could about the disease because he had a family member with it... He explained how things [UI] would progress and what to expect...I learned more from him than anybody or from reading books and pamphlets.</p> <p>It is important that you [caregiver] know that they [care providers] appreciate what you know that works [about in-home care] and that they [care providers] have some understanding of what works as well.</p>
<b>Not understanding</b>	<p>I [caregiver] don't think they [care providers] really understood what his condition was and how he [care recipient] had deteriorated over the past few weeks ...and what help and information I needed and how I needed this help and information [for in-home care].</p>
<b>Encouraging knowledge seeking</b>	<p>Home care was good, I'd asked them questions about what we [caregiver and care recipient] should do and ...yes, that's what you do [care provider response to facilitate UI KT]. One gal [care provider] said anytime you have a problem just phone me at her cell number. I gave her my cell phone and she would always call me if something came up [regarding</p>

	learning about home care and/or UI care].
<b>Impeding knowledge seeking</b>	<p>They [care providers] look...over you [caregiver] when you ask a question about how to do his [care recipient] bath ... they weren't paying the slightest bit of attention to me.</p> <p>Doctors, I [caregiver] always felt that they don't give people credit at all...One doctor said to me how do you know he has blank spells, and how do you know that it wasn't a seizure or it wasn't a...I said I don't. I'm just telling you that he wasn't there, he was absolutely blank. He didn't believe a word I was saying, because how was I to know...I was just trying to enlighten them [share knowledge with care providers].</p>
<b>Listening</b>	Allow the person involved [care recipient] to be listened to and have some say in how things are done. Just listen to her [care recipient] and see what she is trying to say to you [caregiver and care provider]...If you try to tune into what she is trying to communicate to you, it helps you [caregiver and care provider work together].
<b>Not listening</b>	So many people could be a lot more help, if they [home care providers] would just listen, and they don't. It's like they think I don't know anything because I don't have an education.
<b>Trusting</b>	I [care recipient] learn from the people [care providers] whose hearts are in it – they care and are always coming up with something new to do. They [care providers] care about how you are feeling – you [caregiver and care recipient] are in your home, that is what homecare is supposed to be about. It's kind of nice when someone comes into your home and cares enough - loving in a sense. You know and you can trust them.
<b>Not Trusting</b>	It gives you [caregiver] a bad feeling when...different ones [care providers] come in the door. You don't know them and wonder if they will be able to handle him [care recipient] and if you can trust the answers they might give to your questions [regarding care recipient's care].

<b>Supporting Interview Data Used to Create Categories and Core Variable of Study 2: Translating Knowledge Through Relating</b>		
<b>Supporting Interview Data for inextricably linked intertwining relational and translating interactions relevant to KT to manage UI care.</b>	<b>Categories</b>	<b>Core Variable Social Process</b>
<ul style="list-style-type: none"> <li>We [caregiver, care recipient and provider] refer to this [information shared by physicians and hospital staff] every day to learn about my condition.</li> <li>“They [care recipients and family caregivers] can be very creative ... because they are living with the problem ... I will say ... I really learned [UI management] ... from what they shared with me.</li> </ul>	<b>Living with the Problem</b>	<b>Relating</b>
<ul style="list-style-type: none"> <li>If the family caregiver is entering into the sharing and learning process ... you really have to listen to them to promote their comfort and learning.”</li> <li>“It [UI] can be addressed .... [We] talk about how to do this so that we promote their [family caregiver and care recipient] comfort.”</li> <li>“The new providers are more stressed than we are as caregivers.... The more they come, the more relaxed they become with me. They came to know my ways.”</li> <li>“She [family caregiver] is one that I would like to think of as my friend right now. There is a deeper relationship and comfort [between us] ... as we worked together ... we learned how to relate.</li> <li>Even a few moments with someone can set them at ease.</li> </ul>	<b>Developing Comfort</b>	
<ul style="list-style-type: none"> <li>Each person [caregiver and provider] contributes [to work together], “I’ll do that if you will do that, and we build a little more time as each of us is familiar with what and how the other does something. It’s a mutual thing because each of us is equal.</li> <li>As I worked with the caregiver and shared my knowledge, I learned that she really knew what she was doing. I did well to take the knowledge that she had to offer.</li> </ul>	<b>Nurturing Mutuality</b>	<b>Relating</b>
<ul style="list-style-type: none"> <li>“Providers have to be confident and show family caregivers that we do have knowledge and that we will explain the rationale [for UI management] and listen ... and build their [caregivers] confidence.”</li> <li>“Just make them [family caregivers] feel like they are doing a good job [of learning how to manage UI] ... So I will say, you are doing an excellent job.”</li> </ul>	<b>Building Confidence</b>	

<b>Supporting Interview Data</b>	<b>Categories</b>	<b>Core Variable Social Process</b>
<ul style="list-style-type: none"> <li>We work with them [family caregivers and care recipients] to support them in the management of UI.</li> <li>For example, I might say: “You can manage ... your condition ... and this is how to do it.” So they are empowered. They take back the control that they have lost.</li> <li>This is a medical condition and these are the options that we have to deal with it.</li> </ul>	<b>Managing In-home Care</b>	<b>Relating</b>
<b>Supporting Interview Data for inextricably linked intertwining relational and translating interactions relevant to KT to manage UI care.</b>	<b>Categories</b>	<b>Core Variable Social Process</b>
<ul style="list-style-type: none"> <li>“I learn best by doing and experience”.</li> <li>“I combine my experience or what I have seen across many homes with what I learned more formally. Then I apply this information as I work with people in the home.”</li> <li>I learn by doing – I figure out how to do it just by watching ... I was doing it [UI care] in a different way ... But I learned better techniques by watching the care worker so then I could help him [spouse] with moving and skin care.</li> </ul>	<b>Building Experiential Knowledge</b>	
<ul style="list-style-type: none"> <li>“As I ... ease over time into what needs to be done and how I go about it [learn about UI], I involve and work with home care.”</li> <li>I start with broad assessment.... it assists us in easing into conversation about UI so I commence with questions about mobility, nutrition etc. as we work with them [caregiver, care recipient].</li> <li>It’s hard because I may not have enough time to engage in the social aspect [sharing UI information] and ... work with them to make them [caregiver and care recipient] comfortable.... So I will tell them that I will be back to see them tomorrow.</li> <li>As we work together ... I realized it was important for him [care recipient] to have a laugh ... it’s like connecting with him and giving him a little bit of hope that something can be done to manage his condition.... So I tried to make his day a bit brighter by sharing a bit of humour with him... and then we would talk about how to do his care.</li> </ul>	<b>Easing Into a Working Relationship</b>	<b>Translating Knowledge</b>

<ul style="list-style-type: none"> <li>• We [caregiver, care recipient, and paid provider] always have a laugh while we work. It gets us to work a bit closer to make the best care for my spouse.</li> </ul>		
<ul style="list-style-type: none"> <li>• I share my observations [about in-home signs of UI] with them [family caregiver and care recipient] and invite them to contribute to the conversation about how to manage UI.... I also teach the clients and then ask them to share with me how that teaching information might work for them.</li> <li>• “I said ... Is something not working? Is there anything we can do differently [to address how to learn]?”</li> </ul>	<p><b>Facilitating Knowledge Exchange</b></p>	
<ul style="list-style-type: none"> <li>• “They [paid providers] know and learn my habits [for in-home care] and I learn their habits. “I said, ‘As I work with home care clients, I am explaining as I go ... I explain the reason for doing something [care technique]’.”</li> <li>• “This is what we can do. This is what we can’t do. So let’s see how we can get to where we need to go [with lifting into the tub].”</li> </ul>	<p><b>Fine-tuning Knowledge Exchange</b></p>	<p><b>Translating Knowledge</b></p>
<ul style="list-style-type: none"> <li>• I had an idea about what I thought would work [to manage UI]. She [care provider] came up with another idea but it was not working totally. I expanded on the design of the material by creating a wick to draw the urine away from the skin ...We learned together and put it all together right.</li> <li>• “We compiled a little booklet that talks about the problems with my condition and all of the various things that could go wrong and then refer to this information everyday to learn about my condition, so we put it all together.”</li> </ul>	<p><b>Putting It All Together</b></p>	

## CURRICULUM VITAE

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**Post-secondary  
Education and  
Degrees:**

<b>Institution</b>	<b>Department</b>	<b>Degree</b>	<b>Year</b>
University of Saskatchewan	Nursing	BScN (Distinction)	1979
University of Saskatchewan	Nursing	Masters	2004
University of Western Ontario	Health Sciences	PhD (c)	2008

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University of Saskatchewan			
Graduate Studies Scholarship	\$15,000 x 2 years		2002-2004
Canadian Institutes of Health Research (CIHR)	\$47,250		2004-2005
Ontario Government Scholarship	\$15,000		2006-2007
University of Western Ontario			
Faculty of Health Sciences Scholarship	\$8,000		2006-2007
Canadian Nurses' Foundation			
Dr. Ann C. Beckingham Scholarship	\$6,000		2007-2008
Social Science and Humanities Research Council (SSHRC)			
Doctoral Fellowship	\$20,000 x 2 years		2007-2009

University of Western Ontario		
Faculty of Health Sciences Scholarship	\$8,000	2008-2009
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### **Related Work Experience**

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Canadian Council on Health Services Accreditation Field Educator, Ottawa, Canada, 1998-1999

Director of Resident Care, Valley View Centre, Saskatchewan Department of Social Services, Moose Jaw, Saskatchewan, 1998 – 2002

Research Associate, Dobson, R., Forbes, D., Henry, C., Keegan, D., Lachaine, J., Taylor, J., Zello, G. *Interdisciplinary Collaboration in Community Practice: Assessing Attitudes and Participating in Team Based Health Care*. (CIHR & others). University of Saskatchewan, Saskatoon, Saskatchewan, (2004-2006)

Research Trainee, Forbes, D. PI, Jansen, L. *Role of Home Care in Dementia, Alzheimer Society Research Program: Research Grants and Training Awards*, University of Western Ontario, London, Ontario, (2005-2007)

Assistant Professor, Probationary, University of Saskatchewan, College of Nursing (2009-2012)

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### **Unpublished Thesis**

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