

Regaining Control:

A Grounded Theory of Older Adults with New-Onset Urinary Incontinence

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A Dissertation submitted to the

Graduate School - Newark

Rutgers, The State University of New Jersey

in partial fulfillment of the requirements

for the degree of

Doctor of Philosophy

Graduate Program in Nursing

written under the direction of

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Newark, New Jersey

May 2014

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ABSTRACT OF THE DISSERTATION

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Abstract

Rational for the study: Despite an extensive body of literature about urinary incontinence (UI), and it being a ‘hazard of hospitalization,’ no studies about new-onset UI from the perspectives of older adults were identified. **Methodology:** University and Hospital Institutional Review Boards approved this study. Data sources included: almost 170 hours from 61 field visits between December 2009 to May 2012, interviews with 14 participants, and their medical records. Grounded Theory methodology was followed (Glaser, 1978; 1992; 1998; 2002; Glaser & Strauss, 1967). **Theoretical Findings:** In sharing experiences with new-onset UI, the main concern of the participants, loss of control, emerged. Triggered by biological damage caused by illness or injury, the substantive theory of *Regaining Control* illuminates episodes of loss of bladder control as a part of a much broader concern: physical, spatial-temporal, and social aspects of loss of control. This complex, iterative and overlapping three-phase process - Transferring Control, Exercising “Wobbly” Control, and Adjusting to Degree of Control Regained – describes and explains the behavioral patterns of how participants worked to resolve, or attempted to resolve, loss of control. Three conditions influence this process: biological recuperation, understandings of hospitals, and provisional controllers. **Conclusion:** *Regaining Control* contributes to the literature about UI, control, and patient-centered care. Findings provide

theoretical groundwork that addresses the social and environmental factors previously identified as a gap in the UI literature (Palmer, 2004). Three important perspectives of control are offered: the action-oriented nature of control, the process of control sharing between patients and provisional controllers, and the change in control that occurs during hospitalization.

keywords: control, Grounded Theory, incontinence, new-onset urinary incontinence, older adults, patient-centered care, urinary incontinence

Acknowledgement

‘Doing’ this dissertation study would not have been possible without a long list of individuals and groups that supported my pursuit to understand ‘what was going on’ with older adults who were admitted to the hospital and experienced new-onset UI. First and foremost, I thank the fourteen individuals who consented and shared their experiences to help “a nice young lady” learn about new-onset UI from their perspectives. Next, I humbly thank the hospital workers from all levels of the organizational chart who guided me through formal and informal processes to ‘gain entry to the field.’ Their support and encouragement are examples of the immeasurable, and often hidden, carework done everyday in efforts to improve hospital care practices.

Next, I thank my formal academic professors for their patience and understanding. During my admission interview for graduate studies, Dr. Joanne Robinson encouraged my research interest in gerontological nursing, specifically urinary incontinence (UI), served as my advisor, and supervised my research work with her clinical trial of behavioral treatments for men with UI after prostatectomy. I extend a special thank you to the four members of my dissertation committee. Dr. Linda Flynn taught several core graduate courses, as well as supervised my independent study of hospital protocols for UI. Her shared expertise about the nurse workforce and work environments has been invaluable for me to better understand carework in the hospital setting. Long ago, Dr. Susan Reinhard recognized my passion for improving care for older adults through the teaching of nursing students. Her commitment to support my doctoral education motivated to complete it. Dr. Teri Lindgren provided exceptional insight to facilitate my learning the skills of ethical and naturalistic inquiry. Last, but not by any means least, Dr. Elise Lev, Chair, who introduced me to methodology for inductive inquiry and “tolerated my confusion” best – thank you.

Specific to Grounded Theory Methodology, I appreciate this methodology that Dr. Barney Glaser and Dr. Abram Straus published in 1967. It was a challenge to understand the many variations of this method. During my study, it was essential to work among others ‘Doing Grounded Theory.’ Throughout my ‘Discovery’ there were many Grounded Theorists who helped me better understand and implement this research method. I extend special thanks to members of a Rutgers peer group: Dr. Noel Kerr and Dr. Ellen Shannon. Ellen and I attended a Grounded Theory Seminar to work with others “Doing” the method. Noel was an exceptional leader who kept us on task with the methodology. Their emotional and methodological support was essential. During the Grounded Theory Seminars Dr. Barney Glaser, Jillian Glaser, Dr. Otis Simmons, Dr. Helen Scott, Dr. Judith Holton, Dr. Andy Lowe, and Dr. Tom Andrews provided a nurturing environment. I am indebted to Dr. Tina Johnston – a professional consultation that lead to a collegial relationship.

Additionally, I am indebted to those who kept the faith when mine faltered. With that in mind, I acknowledge with much love and gratitude: colleagues and students at the Evelyn L. Spiro School of Nursing and campus-wide at Wagner College, Dr. Christine Bradway, Jane DeFazio, Bob Fisher and ‘chicks,’ Dr. Sherry Greenberg, the ‘Hillside Crew,’ Dr. Diane McGivern, Dr. Mathy Mezey, ‘Team Hartford,’ ‘Hunter Crew,’ The Castronovo Family, The Dowling Family, The Hartmann Family, The Tepper Family, and The Zustovich Family.

This work was funded by the Jonas Center for Nursing Excellence and by the Epsilon Mu Chapter of Sigma Theta Tau International Nursing Honor Society. I am very grateful to Mr. and Mrs. Jonas for their financial and personal investment. They fuel my commitment to improve healthcare of older adults through nursing.

My final acknowledgement is that my Castronovo men – sons, Nicholas, Robert, Steven, and, husband, Steven - were, and continue to be, pillars of faith, strength, and love!

Dedication

This work is dedicated in loving memory of my parents,

Robert and Joan Dowling,

and a dear friend,

Christina Fisher.

Our interactions during your times of ‘crisis’ continue to shape me as a nurse clinician, nurse educator, and nascent nurse scientist . . .

and, Dr. Ethel Mitty.

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Table 1 – Abridged Overview of Regaining Control

Chapter One

Introduction and Theoretical Perspective

Urinary incontinence (UI) is an involuntary loss of urine sufficient to be characterized as a problem (Fantl et al., 1996; Resnick & Ouslander, 1990) and affects approximately 26 million Americans at some point during their lifetimes (National Institutes of Health: NIH, 2008). The management of UI costs an estimated \$14 billion annually (NIH, 2008) and is a marker of frailty in community-dwelling older adults as well as a predictor of nursing home placement (Holroyd-Leduc, Mehta, & Covinsky, 2004; Thom, Haan, & Van Den Eeden, 1997). Identified as a prognostic factor for functional ability after a cerebral vascular accident (CVA) (Meijer, Ihnenfeldt, de Groot, Limbeek, Vermeulen, de Haan, 2003) and a significant factor related to post-hospital physical function (Lee & Rantz, 2008), UI is also associated with psychological distress including depression, poor self-rated health, and social isolation (Bogner et al., 2002; Fantl et al., 1996; Thom et al., 1997). UI affects informal caregivers, as well, by causing increased strain on family caregivers (Cassells & Watt, 2003; NIH, 2008).

Risk factors for UI include older age, female gender (Holroyd-Leduc & Straus, 2004; Markland, et al., 2008; NIH, 2008), caffeine intake (Fantl et al., 1996; Holroyd-Leduc & Straus, 2004), and limited mobility (Fantl et al., 1996; Holroyd-Leduc & Straus, 2004). The relationship between UI and race has not been well-developed, but some evidence noted a significantly higher prevalence rate among white women in comparison to black women (Markland, et al., 2008). Other risk factors are comorbidities such as impaired cognition, diabetes, obesity, smoking, fecal impaction, malnutrition, depression, delirium, low oral fluid intake, environmental barriers, Parkinson's disease, CVA,

chronic obstructive pulmonary disease, arthritis and back problems, and hearing or visual impairment (Brown, Sawaya, Thom, & Grady, 1996; Dowling-Castronovo, 2004; Fantl et al., 1996; Holroyd-Leduc & Straus, 2004; Kresevic, 1997; NIH, 2008; Shamliyan, Wyman, Bliss, Kane, & Wilt, 2007; Thom et al., 1997). Certain classes of medications, such as diuretics and narcotics, are associated with UI (Fantl et al., 1996; Finkelstein, 2002; Holroyd-Leduc & Straus, 2004). In the hospital setting, incontinent patients were more likely to have an indwelling urinary catheter than continent patients (Gillick, Serrell, & Gillick, 1982). Urinary incontinence is associated with falls among hospitalized patients (Krauss et al., 2005). Gender-specific risk factors for UI among women include pregnancy, vaginal delivery, episiotomy, hysterectomy (Brown et al., 2000; Holroyd-Leduc & Straus, 2004), and estrogen depletion (Fantl et al., 1996; Holroyd-Leduc & Straus, 2004; NIH, 2008). For men, surgery and radiation treatment for prostatic hyper trophy or carcinoma are associated with UI (Fantl et al., 1996; Hunter, Moore, Cody, & Glazener, 2004; NIH, 2008). Pelvic muscle weakness is also a risk factor for UI (DeLancy, 1994; Holroyd-Leduc & Straus, 2004; Kegel, 1956), albeit additional study in the male population is needed.

Evidence-based clinical guidelines have been developed to guide assessment and treatment of UI (see Appendix A – Review of Clinical Guidelines for UI). Clinically, there are two categories of UI: transient, or acute UI, and chronic or established UI. First, transient or acute UI, is characterized by the sudden onset of potentially reversible UI symptoms (Ermer-Seltun, 2006 & Specht, 2005) (see also Appendix B – Transient/Acute Urinary Incontinence), and generally has a duration of less than six months (Specht, 2005). However, there may be cases of acute UI that are neither transient nor reversible,

such as UI secondary to a spinal cord injury. This latter example then becomes one type of the second category, which is UI of a chronic nature or established UI (see Appendix C – Established UI).

The medical and nursing literature does not fully explain or discuss transient or acute UI. One study about transient UI among patients in a Singapore hospital was found (Ding & Jayaratnam, 1994). This prospective study (n=254) reported a 22% prevalence rate for UI. One-fourth of these cases were transient UI that resolved after causes (Appendix B) were identified and treated. No studies using the term “acute UI” were found. Sier and colleagues (1987) first used the term “new-onset” UI based upon their finding that 12% of incontinent hospitalized older adults were continent at time of admission and developed UI during hospitalization.

In a prospective study of 227 older adults admitted for medical reasons to a large urban hospital in the US, Kresevic (1997) found that 36% experienced new-onset UI. Compared to continent patients, those with new-onset UI were significantly more likely to be women; have longer hospitalizations; experience compulsory bedrest; have a urinary tract infection; be physically restrained; and be more dependent with activities of daily living. Multiple regression analysis found that depression, malnutrition, and dependent ambulation were significant risk factors for new-onset UI.

Palmer and colleagues (2002) conducted a retrospective secondary analysis of 6515 women hospitalized for hip fracture who were continent prior to hospitalization. Twenty-one percent experienced hospital-acquired incontinence, defined as UI, fecal incontinence, or both. Although the incidence of new-onset UI cannot be extrapolated from this finding, it seems new-onset UI and hospital-acquired UI both refer to UI that devel-

ops during hospitalization. A significantly higher incidence of hospital-acquired UI was reported for patients who were over 80 years of age; African-American; admitted from some place other than their own home; confused; used mobilization assistance prior to hip fracture; required assistance with ambulation; were malnourished; and had higher morbidity. After controlling for confounding variables, admission from a long-term care (LTC) facility, confusion, use of wheelchair or assistive device for ambulation, and pre-fracture need for ambulation assistance significantly increased the odds for the development of hospital-acquired incontinence.

Limitations identified by the researchers in the aforementioned studies addressed the limited accuracy of reported incidence rates. The data used in both studies described above (Kresevic, 1997; Palmer et al., 2002) were based on documentation of patient status at time of admission and discharge. This method missed cases of UI that occurred during hospitalization, which resolved before discharge, and cases that occurred and were not documented.

Evidence-based clinical guidelines (Appendix A) that might guide nursing interventions for new-onset UI have failed, for the most part, to be applied in practice (Bayliss, Salter, & Locke, 2003; Watson, Brink, Zimmer & Mayer, 2003). The guidelines primarily address how to assess and treat established UI in LTC and community settings rather than new-onset UI in the hospital setting. The fact that few hospitals have developed guidelines for UI (Dowling-Castronovo, 2005; Wagg, Mian, Lowe, Potter, & Pearson, 2005) may explain why assessment and treatment of UI in hospitals has been reportedly inadequate (Cooper & Watt, 2003; Fonda & Nickless, 1987). This may also explain why the interventions of choice for UI in hospitals describe containment with catheters,

collection devices, or absorbent products (Cheater, 1993; Cooper & Watt, 2003) rather than recommended intervention with behavioral modification (see Appendix A – in particular Dowling-Castronovo & Bradway, 2008; 2012). However, interventions put forth in clinical guidelines (Appendix A) were not developed from research of hospitalized older adults with new-onset UI. It is reasonable to suggest that clinical guidelines have not been applied in hospitals because the recommended interventions are not relevant to new-onset UI and/or to hospitalized older adults. As such, it is not known how to best address UI in this focus population. Perhaps the most important explanation for the lack of attention that UI has received in hospitals is that it has been almost exclusively studied from the perspective of medical and nursing staff (Connor & Kooker, 1996; Cooper & Watt, 2003; Dingwall & McLafferty, 2006; Fonda & Nickless, 1987; Hancock, Bender, Dayhoff & Nyhuis, 1996) and not from the perspective of hospitalized older adults. Although some evidence demonstrated varied treatment preferences for UI among 117 hospitalized older adults with and without UI, and in comparison to their hospital staff and designated proxies (Pfister et al., 2007), the preferences and perspectives from patients with new-onset UI have not been documented.

The Concern to be Addressed

Despite an extensive body of literature about UI, a review of the literature found no studies about new-onset UI from the patient perspective. This Grounded Theory ([GT] Glaser, 1978; 1992; 1998; 2002; Glaser & Strauss, 1967) study provides a substantive theory to understand how hospitalized older adults with new-onset UI address their main concern.

The Phenomenon of Interest

The phenomenon of interest was new-onset UI in hospitalized older adults. Definitions of terms used for the purpose of this study:

Hospital – a state licensed acute health care institution where acutely ill or injured individuals receive medical and surgical care;

Hospital Inpatient Rehabilitation Unit – a hospital unit that admits patients from acute care units for rehabilitation. Patients typically have diagnoses such as stroke, femur/hip fractures, joint replacement, arthritis, and cardiac disorders;

Hospitalized older adult – a man or woman age 65 years or more who is currently on a hospital inpatient rehabilitation unit continuing hospitalization for treatment of an acute alteration in health;

Urinary Incontinence - any sign or symptom of any amount of involuntary loss of urine;

Urinary Continence – no sign or symptom of any amount of involuntary loss of urine;

New-onset UI - UI experienced during hospital admission by a hospitalized older adult who was continent at time of hospital admission and experienced no UI within 6 months prior to hospital admission.

The Purpose of the Research

The purpose of this study was to discover theoretical explanations for how hospitalized older adults with new-onset UI view their condition. The goal of a Grounded Theory (GT) study is to discover the main concern of a focus population and document how that population works to resolve that concern (Glaser, 1978; 1992; 1998; 2001; 2002; Glaser & Strauss, 1967). With the use of GT methodology the researcher examined the main concern of older adults with new-onset UI and discovered a theory of how they

worked to resolve that main concern. The theoretical findings from this study contribute to the literature about control, patient-centered care, and UI and may help to inform policy to improve hospital care.

Foundational Assumptions

The patient, and/or caregiver, and/or significant other may perceive new-onset UI as a problem (Abrams et al., 2003). Hospital workers, who in the hospital or medical setting become temporary members of a hospitalized older adult's social network, may also perceive involuntary urine loss as a problem. Using GT (Glaser, 1978; 1992; 1998; 2001; 2002; Glaser & Strauss, 1967) the investigator analyzed data to identify (1) the main concern of hospitalized older adults with new-onset UI and (2) the core category to help identify/understand/explain their behaviors that addressed their main concern.

Participants were recruited by the principle investigator (PI) from a hospital inpatient rehabilitation unit in an effort to maximize the feasibility of this investigation. The PI believed that recruitment and retention of participants from this setting would be more feasible than from other hospital units where patients are more acutely ill. In turn, these patients were less likely to experience fatigue during an interview. In considering the protection of human subjects, this was deemed an important consideration that outweighed the risk of patients having issues with recollection.

Significance

First, with the exception of several studies (Krešević, 1997; Palmer et al., 2002; Sier et al., 1987, Zisberg, Gary, Gur-Yaish, Admi, & Shadmi, 2011) the epidemiology of new-onset UI is essentially unknown nor is its natural history. Despite the fact that incontinence has been identified as a hazard of hospitalization for older adults since the 1980s

(Creditor, 1993; Fernandez, Callaghan, Likourezos, & Leipzig, 2008; Gillick et al., 1982; Resnick & Yalla, 1985) there is little research about the onset of UI in the hospital setting. The prevalence of UI in hospitalized older adults ranges from 13% – 43% (Berlowicz, Brand, & Perkins, 1999; Cheater, 1993; Dowd & Campbell, 1995; Halm et al., 2003; Palmer, Myers, & Fedenko, 1997; Schultz, Dickey, & Skoner, 1997). The incidence of UI, or new-onset UI, ranges from 12-36% of hospitalized older adults (Kresevic, 1997; Palmer et al., 2002; Sier et al. 1987). While risk factors for new-onset UI have been identified (Kresevic 1997; Palmer et al., 2002) no intervention studies have been identified in the literature.

Studies addressing perspectives and concerns of hospitalized older adults with new-onset UI were not found. Hospital nurses believed that the longer UI is present, the more accepting of it an older adult becomes and the less likely it is treatable (Dingwall & McLafferty, 2006). This suggests that there may be a small “window of opportunity” to address new-onset UI. Findings from this current study help to better understand that “window.” In addition, Palmer (2004) noted that there has been little UI research that considers social and environmental factors and suggested that theory development was needed to understand patient perceptions about UI. Findings from this study provide initial theoretical groundwork addressing the knowledge gap about the concerns and behaviors of hospitalized older adults with new-onset UI. This new knowledge may provide the basis for future research and policy initiatives that target hospital care.

Summary

Despite the development of evidenced-based guidelines for UI assessment and care, increased number of continence specialists, and greater public awareness, the prob-

lem of incontinence persists (Norton, 2006). Research about new-onset UI in the hospitalized older adult population has been essentially non-existent. This GT study provides initial theoretical underpinnings needed to understand what concerns of hospitalized older adults with new-onset UI and how they work to resolve those concerns. This new knowledge provides a basis for future research aimed to improve hospital care for older adults who are likely to experience new-onset UI.

Chapter Two

Literature Review

There is a vast amount of literature about urinary incontinence (UI) but little about new-onset UI in the hospital setting. As such, the UI literature was reviewed *a priori* to understand the themes in the UI literature that may relate to new-onset UI. Two questions drawn from the review of GT methodology literature (Glaser, 1978, 1998, 2001; Glaser & Strauss, 1967) guided this review: 1) what about UI, specifically new-onset UI, may be considered a professional problem; and 2) what about new-onset UI may be the main concern for hospitalized older adults? It was important to analyze the UI literature in an effort understand the difference between a professional problem, and the problem, or main concern, of hospitalized older adults. In accordance with GT methodology, the perspectives derived from this *a priori* review of the literature were contingent on simultaneous data collection and analysis for the main concern of the participants in the substantive area.

Background of the Phenomenon-New-onset UI

The rate of incidence of new-onset UI has been documented in the medical and nursing literature (Palmer et al., 1997; Palmer et al., 2002; Sier et al., 1987; Kresevic, 1997; Zisberg et al., 2011). These published studies documented UI occurring among hospitalized older adults who were continent at time of admission (Kresevic, 1997; Palmer et al., 2002; Sier et al., 1987). Together these studies provide a basic view of the epidemiology and demography of individuals who experience the condition.

A prospective study examined new-onset UI, defined as UI that an older patient, who was continent at time of admission, developed during hospitalization (Sier et al.,

1987). The study described UI among 363 admissions for whom demographics and UI prevalence were reported. Slightly less than half of the sample consented to additional data collection of which 20 patients experienced new-onset UI - an incidence rate of 12%. This finding likely underreported the incidence of new-onset UI because data were limited to half of the hospitalized older adult sample and self report. The small number of patients with new-onset UI did not support comparative analysis about characteristics among patients with new-onset UI, patients with established UI, and continent patients. Therefore, it was unknown as to what characteristics were unique to those who experienced new-onset UI and might be modifiable.

Kresevic's (1997) doctoral dissertation identified the incidence of new-onset UI, using Sier and colleagues' (1987) definition, to test a predictive model based on an ecological conceptual framework in a sample of 227 hospitalized older adults. Thirty-six percent experienced new-onset UI. This was higher than the findings of Sier and colleagues (1987), which may be attributed to a larger sample size. This may still underestimate the number of cases because data collection points, at time of admission and at discharge, likely missed cases of new-onset UI that occurred and resolved prior to discharge. Compared to continent patients, those with new-onset UI were significantly more likely to be women; have longer hospitalizations; experience compulsory bedrest; have a urinary tract infection; be restrained; be more dependent with activities of daily living; and have higher serum sodium levels (Kresevic 1997). Multiple regression analysis found that depression, malnutrition, and dependent ambulation were significant risk factors for new-onset UI (Kresevic, 1997).

In a hospital in Isreal, Zisberg and colleagues (2011) screened 352 hospitalized older adults for new-onset UI. Via self-report from patients or their available surrogates, researchers documented a 17.1% incidence. In comparison to continent participants, new-onset UI was significantly associated with participants who had indwelling urinary catheters for six hours or longer, wore adult diapers, and were more dependent in their ADLs.

Another study identified a 32% incidence of new-onset UI in a convenience sample of 100 patients hospitalized for hip fractures (Palmer et al., 1997). In a larger study, Palmer and colleagues (2002) found that 21% of 6516 female patients admitted to the hospital for hip fractures experienced hospital-acquired incontinence, defined as documentation of UI, fecal incontinence, or both. The incidence of new-onset UI cannot be precisely extrapolated from this later study. Nevertheless, both studies likely underestimate the incidence of new-onset UI because the data were solely based on documentation - a limitation acknowledged by the researchers. An additional limitation for both studies, similar to Kresevic's (1997) study, was cases of new-onset UI that resolved before discharge were not identified. In comparison to continent patients, those with new-onset UI were significantly more likely to be men and cognitively impaired (Palmer et al., 1997). In addition, hospital-acquired incontinence was significantly associated with admission from LTC facilities, confusion, dependent ambulation, or independently wheelchair bound (Palmer et al., 2002).

It appears that hospital-acquired UI and new-onset UI are similar terms, since both newly occur during a hospitalization. The term hospital-acquired incontinence suggests that this type of UI is amenable to prevention, as well as intervention strategies, and led to another avenue of the literature in which one abstract was identified. Paillard and

Resnick (1984) collected observational data on 102 hospitalized older adults over six weeks and reported a 15% incidence of nosocomial UI. No definition of nosocomial UI was offered, but may be viewed similarly to new-onset-UI. All but two cases of nosocomial UI improved spontaneously as the patients' overall condition improved. The two cases that did not improve were patients who suffered extensive brain damage from Cerebral Vascular Accidents. Conversely, in Kresevic's study (1997), new-onset UI persisted for one year after hospital discharge for one-fourth of participants. (Data collection ended after one year).

In sum, the incidence of new-onset UI in hospitalized older adults ranges from 12% to 36%. Depression, malnutrition, and dependency are risk factors for new-onset UI. Male gender and cognitive impairment are significantly associated with new-onset UI in a population of patients after surgical repair for hip fracture. For women with hip fractures, hospital-acquired UI is significantly associated with admission from LTC facilities, confusion, and mobility impairment. New-onset UI is significantly associated the use of indwelling urinary catheters and adult diapers. Until this current GT study, no known studies of new-onset UI from the perspectives of hospitalized older adults existed.

Related Themes

A critical appraisal of several definitions of UI was informative. In a retrospective study of hospital records, Cheater (1993, p. 1736) used the definition "involuntary excretion of urine in inappropriate places regardless of the amount of urine lost." It is unclear what was considered an inappropriate place. Moreover it is unclear as to whom, the nurse or the patient or another, deemed a place as inappropriate. The International Continence Society's (ICS) old definition of UI, "involuntary urine loss that causes a social or hy-

giene problem”, was deemed inappropriate for biomedical research (Foldspang & Mommsen, 1997). As such, the ICS currently defines UI as a symptom of “complaint of any involuntary leakage of urine” (Abrams et al., 2003, p. 38; Haylen et al., 2009, p. 10). Interestingly, findings from several studies (Jeter & Wagner, 1990; Kinchen et al., 2002; Miller, Brown, Smith & Chiarelli, 2003; Milne, 2000) did not support the contemporary ICS definition because most individuals with UI do not seek professional advice, and, therefore, will not “complain of” urine leakage. In addition, the scientific literature, together with support organizations, such as the National Association for Continence (<http://www.nafc.org>) emphasizes screening for UI because the social stigma of UI prevents individuals from seeking professional care for bladder control issues (Fantl et al., 1996; International Consultation on Incontinence, 2000; Shamliyan et al., 2007). Yet, UI is commonly defined as a symptom - the involuntary loss of urine sufficient to be a problem (Resnick & Ouslander, 1990; Fantl et al., 1996) - which the patient, caregiver and/or significant other may perceive as problematic (Abrams et al., 2003). Health care organizations and providers may also perceive UI as a problem.

Despite the lack of consensus for the definition of new-onset UI, and the lack of information of the natural history of UI, there are over 2000 studies about UI in MEDLINE and CINAHL databases. UI has been studied more from a biomedical perspective rather than from the perspective of those with UI. This *a priori* review of the literature was organized into several sections. The first section is a discussion about the epidemiology and cost of UI in hospitals. The next section, behavioral characteristics of UI, delineates four themes identified in the literature about the non-surgical aspects of addressing UI: 1) strategies to control UI; 2) goals of UI care; 3) clinical guideline translation to

practice; and, 4) factors that influence UI care. The third and last section discusses why UI in the hospital setting is a “professional problem” for nursing and why new-onset UI required an investigation to learn how hospitalized older adults assigned concern to new-onset UI.

Epidemiology and Cost of UI in Hospitals

Variable and poorly articulated UI definitions as well as underreporting and underassessment of UI (Schultz et al., 1997) likely result in data of questionable validity and reliability. Studies illustrated the challenges for the study of UI in hospitals (Cheater, 1993; Dowd & Campbell, 1995; Gillick et al., 1982; Ostaszkiewicz, O’Connell, & Miller, 2008; Palmer, Bone, Fahey, Mamom, & Steinwachs, 1992; Schultz et al., 1997; Sullivan & Lindsey, 1984. One study described the financial ramifications (Morris et al., 2005).

A study of 429 consecutive hospital admissions reported a 27% incidence rate of UI in hospitalized older adults (Gillick et al., 1982). Since UI was defined as “incontinence at least once” (Gillick et al., 1982, p. 647) this is more likely a prevalence rate. Others identified a 19% daily prevalence of UI in hospitalized older adults, but did not delineate new occurrences of UI (Sullivan & Lindsey, 1984). Yet, Cheater (1993) reported a 39% prevalence rate for UI that included patients with indwelling urinary catheters used for UI. Reliability testing indicated that charge nurses reliably identified incontinent patients 90% of the time (Cheater, 1993). Via self-report, 11% of 9191 hospitalized patients experienced established UI, or UI of chronic nature (Palmer et al., 1992).

Discrepancies among UI data collected from hospital records and from patients are noteworthy. A retrospective audit of hospital records found that 1% of patients had an International Classification of Disease (ICD) - UI coded diagnosis despite nursing notes

that documented 13% of patients had UI (Dowd & Campbell, 1995). The fact that 13% is much lower than other reports (Cheater, 1993; Gillick et al., 1982) suggests that the Dowd & Campbell's (1995) retrospective chart audit likely failed to capture cases of undocumented UI that underestimated the actual cases of UI. Since UI is often viewed as a symptom - not a diagnosis - this may explain the discrepancy between ICD-UI coded diagnosis and nursing documentation.

A study that compared data collected directly from patients to data collected from hospital admission records (Schultz et al., 1997) demonstrated that UI data solely collected from hospital records does not adequately capture cases of UI. The patient-data prevalence for UI was 42% in comparison to only 0.1% of the admission records that recorded this information. Other findings support the need to collect about UI directly from the patient. Ostaszkiewicz and colleagues (2008) found that 34% of their sample (n=369) reported history of UI prior to hospital admission. Less than half of these cases were documented in hospital records.

The financial implications of UI in the hospital setting were addressed by one study conducted in Australia (Morris et al., 2005). Twelve percent of the daily cost of hospitalization for a patient in single room occupancy was for care of incontinence. This cost included staff time for assessment, toileting assistance, clothing and linen changes, incontinence products, catheter care, and laundry services. Unfortunately, findings from this study cannot be generalized to the United States because the majority of incontinence care in Australia is provided by professional staff (registered nurses [39%], enrolled nurses [44%]) whereas in the United States professional nurses have delegated incontinence care to nursing assistants (Cartier, 2003). Although the cost analysis does not re-

flect secondary costs, such as incontinence-related falls or skin breakdown, it supports the need for an increased understanding of, and interventions for, UI.

In sum, epidemiological studies of UI likely underestimate its incidence and prevalence because study data has mostly relied on hospital documentation that does not accurately record all actual cases of UI. The little that is known about costs of UI in hospitals cannot be generalizable to US hospitals or to new-onset UI, but the findings do support the need for further study to understand how to provide the most efficient and cost-effective care for UI in hospitals.

Behavioral Aspects of UI

Analysis of the UI literature, detailed below, revealed four themes that informed this study, from its beginning, with respect to new-onset UI: strategies to control UI, goals of UI care, clinical guideline translation to practice, and factors that influence UI care. Regardless of UI type or setting, containment and concealment strategies are the primary strategies used by individuals and recommended by health professionals. Within health care institutions it is unclear how to best address UI so that both the needs of the institution and the individual are met. Clinical guidelines for UI have not been successfully translated into practice. Many factors influence UI care.

Strategies to control UI. A substantial amount of literature supports behavioral strategies - pelvic muscle exercises, toileting schedules, dietary changes, and pharmacological - to control UI (See Appendix A – Review of Clinical Guidelines for UI). However, these strategies are not the primary strategies implemented. Two descriptive studies of community-dwelling older adults with UI suggested that containment and concealment strategies were the initial strategies adopted to control UI in this population (Mitteness &

Barker, 1995; Skelly & Boblin-Cummings, 1999). UI is considered controlled if kept invisible and social routines are maintained (Mitteness & Barker, 1995). In other words, control is not about the actual involuntary leakage of urine but, rather, speaks to containment and concealment strategies that facilitate sociability. Containment strategies typically included absorbent products such as reusable and disposable adult briefs (adult diapers), perineal pads, and incontinence pads to protect the bed from urine. Mitteness and Barker (1995) found that if absorbent products were not affordable, then creative and often complex containment strategies were implemented, such as using towels, “preventive peeing”, and collection devices, such as cooking pots. Concealment strategies are often the same as containment strategies, but performed in an effort to conceal incontinence. For example, absorbent briefs contain and conceal incontinence. In a different way, concealment strategies included fastidious cleansing of self, clothing, and the environment to conceal incontinence odor (Mitteness & Baker, 1995). Dowd (1991) described how women who were “in charge of UI” effectively contained and concealed their UI and, as a result, were able to maintain social routines. Independent use of containment and concealment strategies by community-dwelling older adults required adequate cognitive capacity, financial resources, energy and strength, social skills and supports, physical functioning, and social investment (Mitteness & Barker, 1995). The term “social investment” is not clear.

Containment and concealment strategies were also the main strategies recommended by health care providers (Bayliss, Maggie, Locke, & Salter, 2000; Boblin & Skelly, 1999; Wagg et al., 2005) and used for nursing home residents (Tannenbaum, Labrecque, & Lepage, 2004). With respect to LTC environments, Jirovec and colleagues

(1998) found that the institutional environment fostered the containment and concealment of UI rather than promote the individual's bladder control. Routine nighttime nursing rounds were performed to check and change wet and soiled absorbent products on incontinent nursing home residents (Cruise Schnelle, Alessi, Simmons, & Ouslander, 1998). Nursing assistants perfumed themselves prior to performing incontinence care for nursing home residents in their efforts to conceal urine odor (Jervis, 2001). In addition to the containment and concealment of incontinence, Beber (1990) found that those who used absorbent briefs experienced improvements in skin integrity and social interaction. Improved social interaction was linked to containment products; however, some residents objected to wearing "a diaper" (brief). Staff felt that briefs lessened workload, improved aesthetics, and promoted mobility, all of which enabled residents to leave the unit for socialization. No other studies were found that supported Beber's findings.

In hospitals, containment and concealment strategies are also the primary strategies used to address UI. Hospital nurses reported that basic nursing education often focused on containment and concealment (Cooper & Watt, 2003; Dingwall & McLafferty, 2006). Evidently, these strategies are also implemented for patients without UI. A study (Ostaszkievicz et al., 2008) of hospitalized patients in Australia that reported a UI prevalence rate of 22%, also reported that 60% of patients used some type of containment product (n=447). The researchers suggested a lack of understanding about product usage. It is unclear whose lack of understanding - the staff or patients or both - contributed to the use of containment/concealment products when UI was not present. It can be argued that patients are, in fact, continent when containment and concealment products do what they are supposed to do. Patients feel that the products control their urine loss and allow social

acceptability; therefore, the patients feel continent. Although this possible patient perspective has not been explored, a correlation study examined the relationship of ‘continence aids’, indwelling urinary catheters and adult diapers, and new-onset UI (Zisberg et al., 2011). The term ‘continence aids’ connotes that UI is contained and, thereby, continence is achieved. In another study, hospital nurses considered a patient continent when products kept a patient dry and who used absorbent pads to avoid walking to the bathroom (Dingwall & McLafferty, 2006).

In sum, containment and concealment strategies are commonly used to care for UI. For the community-dwelling older adult, these strategies require a complex set of resources and are typically self-initiated to maintain social acceptability. These strategies are also common in nursing homes and hospitals. Although not delineated in the literature, it is likely that established UI, or chronic UI, was the prevalent type of UI in these settings. Inasmuch as no study described assessment and identification of the etiology of UI, it is reasonable to suggest that cases of transient UI managed with containment and concealment strategies controlled rather than treated transient UI, which subsequently became established UI. The finding that containment and concealment strategies seem to be used for both incontinent and continent hospitalized patients needs further investigation.

Goals of UI care. For individuals with UI, the essential goal of institutional care is to preserve skin integrity. The literature suggests that this may be achieved when UI care is individualized. UI care will vary based on an assessment and plan of care that addresses the characteristics of individuals with UI. Yet, institutional UI care follows formal policies and procedures that do not consistently account for these individual charac-

teristics. The processes of institutionalizing UI care and individualizing UI care have different goals and methods. In nursing homes, care practices for UI disrupted the nighttime environment and were not consistent with institutional policies (Cruise et al., 1998; Schnelle et al., 1999; Schnelle, Ouslander, Simmons, Alessi, & Gravel, 1993a; 1993b). Nighttime UI care included staff turning on lights to check and change wet absorbent products. These activities were associated with substantial sleep disruption for incontinent residents (Cruise et al., 1998; Schnelle et al., 1993a). Institutional protocols, which stated that UI care was to be provided every two hours, were not consistently followed at night. The data indicated that residents received this care on average every three to four hours (Cruise et al., 1998; Schnelle et al., 1993a).

In an individualized intervention study, the delivery of care for UI was based on risk for skin problems: residents at low risk received incontinence care every four hours while high risk residents received incontinence care every two hours (Schnelle et al., 1998). Despite skin being exposed to higher volumes of urine, the low-risk group did not show changes in skin integrity. Both groups had significant improvements in blanchable erythema measures. Another study used the same individualized nighttime care intervention with added efforts to reduce noise and light levels during care at night for incontinent nursing home residents (Schnelle et al., 1999). This latter intervention significantly decreased noise and sleep disruptions without significantly changing skin integrity. Neither study provided details about the products used, such as disposable briefs or cleansing agents.

Various cleansing products are used to remove urine and protect skin integrity. Urine causes the skin to become alkaline and thereby alters its “acid mantle” that protects

the skin from microbial growth (Jeter & Lutz, 1996). In a small study, Byers and colleagues (1995) found that, in comparison to soap and water, a no-rinse cleanser maintained the acidic pH of the skin and reduced skin erythema. Al Samarrai and colleagues (2007) examined the effectiveness of a new incontinence care management product that contained two cleansing wipes in a disposable adult brief. Ninety-five percent of 61 nursing assistants self-reported that this product significantly decreased interruptions during care routines, such as gathering forgotten or additionally needed supplies, decreased care time, and increased the frequency of wipe usage. There was no data about the condition of the residents' skin. The role of products with regard to efficiency of UI care is not fully understood. Specific to this study, it was important to be open to perspectives that participants shared about products.

In hospitals, data indicate that nurses are conflicted about how to care for patients with UI: nurses must balance a patient's overall needs with the needs and processes of the organization. Connor & Kooker (1996) found that over 55% of hospital nurses delayed toileting interventions based on staff convenience. Nine hospital nurses, evaluating an electronic monitoring device for UI, felt that toileting interventions should coincide with routines of the unit (Nikoletti et al., 2004). Similarly, Dingwall and McLafferty (2006) found that although nurses were knowledgeable about the practice of continence promotion based on individualized needs of patients, their care practices for UI satisfied unit routines over the needs of individual patients. These same nurses reported that many patients did not wish to be disturbed during the night for toileting and gladly used incontinence pads, which allowed for a quiet night and was in accord with unit routines. This finding, together with the work of Schnelle and colleagues (1998, 1999), suggests that the

process of care for UI includes a series of choices between individual and institutional needs made between patients and nurses.

In sum, there appears to be a conflict between institutional and individual goals of care for UI. In nursing homes (Cruise et al., 1998; Schnelle et al., 1993a) it may be argued that nursing home policies and procedures for incontinence care were not followed because nursing staff intuitively provided care for UI based on individual, rather than institutional need. The availability of incontinence care products seems to promote containment and concealment strategies, or “check and change” policies. In hospitals, it is unclear if the seemingly low-priority assigned to the care of UI by nurses is justifiable given the acuity of patients in this setting.

Clinical guideline translation to practice. Analysis of the available clinical guidelines (See Appendix A) suggests that the primary goal is to alleviate UI to the greatest extent possible. Clinical guidelines recommend an accurate assessment of UI to determine its etiology. Assessment is largely dependent on available resources. For example, the dipstick method, not a urinalysis, may be the only available resource for the identification of urinary tract infection. Basic UI assessment includes obtaining a history of UI with: a bladder diary and a valid and reliable questionnaire; physical exam that includes evaluation of pelvic floor muscles, pelvic exam, and anorectal exam; and urine testing for infection either by urinalysis or dipstick method. Assessment determines the type of UI after which an individualized treatment plan, essentially consisting of behavioral strategies, can be formulated. Containment and concealment strategies are considered a “last resort” strategy by those who advocate complete assessment and individualized intervention plans. (Surgical interventions for incontinence are beyond the scope of

this review.) A small unpublished survey of 40 American hospitals indicated that assessment and treatment of UI was not adequately incorporated in hospital policies (Dowling-Castronovo, 2005). Other studies have indicated that medical care for community dwelling older adults and nursing home residents with UI is not consistent with clinical guidelines (Gnanadesigan et al., 2004, Watson et al., 2003).

There are few studies specific to the hospital setting. Among care settings, prevailing practice guidelines for UI in the UK were the least developed in hospitals. In comparison to long-term care and community care, prevailing practice guidelines were not as prevalent in hospitals in the UK: 32% had a written continence policy, 49% had a structured training program, and 35% performed a regular audit (Wagg et al., 2008). An unpublished survey (Dowling-Castronovo, 2005) of a convenience sample of US hospitals (n=40) found that 12 (30%) hospitals reported care protocols for evaluation of incontinence. A content analysis of available protocols (n=7) found that, in comparison to guidelines (Fantl et al., 1996), the protocols did not adequately address the history of UI. Only one protocol met guideline criteria for basic assessment of UI. Whether and how this protocol guided practice was not studied.

Across health care settings, UI assessment is not consistent with clinical guidelines. Of three case studies of incontinent individuals in the US, assessment was mentioned in only one case in which diet and use of absorbent products were the only assessment items (Beheshti & Fonteyn, 1998). A survey of UK care homes (n=66) reported that two homes had evidence of a “full assessment”, described as observation of absorbent pad usage and characteristics of urine leakage (e.g., when coughing) and a urinalysis (Rodriguez, Sackley, & Badger, 2007). A study in two rehabilitation units in Ireland

found that less than 9% of incontinent patients had a documented assessment and half lacked a documented etiology (Coffey, McCarthy, McCormack, Wright, & Slater, 2007). In US nursing homes, a study by Watson and colleagues (2003) suggested that incontinent residents were not assessed according to guidelines. Only 2% of female residents had a pelvic examination, almost 15% received a rectal examination, and less than 1% were assessed for type of UI.

A pilot study that audited 13 UK hospitals found a documented history in 66% of UI cases, with less than 50% of UI cases having a documented cause (Wagg et al., 2005). In a larger national audit, a basic history and examination for incontinence, such as a bladder diary (16%) and rectal exam (24%), were documented in less than a third of hospital charts ([N = 3683] Wagg et al., 2008). Also, there was considerable variation in the care provided (Wagg et al., 2008). In response to gaps in the nursing literature, Dingwall and McLafferty (2006) conducted an exploratory study using focus groups with hospital nursing staff (14 professionals and 3 nonprofessionals) to learn how nursing staff in a Scottish acute care of the elderly unit promoted continence. Their findings suggested that hospitalized older adults were more likely to be labeled incontinent without an assessment.

Intervention studies do not fully describe the assessment process. Among a sample of community-dwelling women (n=218) investigators defined inclusion criteria as, "...experiencing involuntary urine loss ... at least twice a week...symptoms of stress, urge, or mixed urinary incontinence based on health history, physical findings, and when indicated, bladder function tests..." (p. 236, Dougherty et al., 1998), but did not detail how the assessment process that led to the specific diagnosis of UI was conducted. In

other intervention studies, UI was determined by nursing home staff (Ouslander, Griffiths, McConnell, Riolo, & Schnelle, 2005) or by research staff who checked only for wetness (Bates-Jensen, Alessi, Al-Samarrai, & Schnelle, 2003). Another study evaluated UI by physical assessment, blood and urine tests, simple uroflowmetry, post-void residual urine sonogram, and a completed 7-day bladder diary (Vaughn et al., 2011). These varied and often vague descriptions of the assessment process suggest that the UI assessment process itself is poorly understood or poorly accepted by researchers. Moreover, it is unclear how the assessment and diagnosis of new-onset UI takes place.

Use of clinical guidelines (See Appendix A) varies among care settings. However, containment and concealment strategies were the primary strategies used across settings (Coffey et al., 2007; Rodriguez, et al., 2007; Wagg et al., 2005). In a 200-bed teaching hospital in Hawaii care practices were inconsistent with clinical guidelines; 51% of nurses surveyed advised patients to “just urinate into the diaper” (Connor & Kooker, 1996, p. 89). Treatment strategies for community-dwelling older adults have included dietary and fluid management, timed voiding, urge suppression, pelvic floor exercises with and without biofeedback, and bladder training (Beheshti & Fonteyn, 1998; Dougherty et al., 1998; and see Appendix A). Bayliss and colleagues (2000) randomly surveyed 300 patients over the age of 60 in the UK who had been recently assessed for UI by a community nurse. Of these, 4% had urine testing and 14% had testing for post-void residual volume. Although it was documented that 27% of the patients had been taught PFMEs, only 7% remembered the teaching. In all cases, the prevailing treatment strategy was recommendation of absorbent pads. Bladder training occurred in 10% of cases. Less than 10% were given fluid and dietary advice, instructed to use a bladder diary, or had

medications review. The researchers concluded that assessment and treatment of UI among community-dwelling older women was not in accord with available evidence.

Prompted voiding is the most common treatment for UI in LTC settings in the US (Bates-Jensen et al., 2003; Ouslander et al., 2005; and see Appendix A). In UK nursing homes, Peet and colleagues (1996) found little evidence of bladder training and no evidence of PFME. Rodriguez and colleagues (2007) found scheduled toileting was implemented in UK care homes less than a third of the time. There was lack of clarity among these studies with respect to differentiating bladder training, scheduled toileting, and prompted voiding.

For rehabilitation units in Ireland, the predominant treatment strategies constipation management, treatment for urinary tract infection, timed (scheduled) voiding, and pharmacological treatment (Coffey et al., 2007). Comparing to predominant clinical guidelines, (Fantl et al., 1992), Hancock and colleagues (1996) determined that two UI interventions used by American hospital nurses were inaccurate. Seven percent of nurses identified the need to increase the length of oxygen tubing as a treatment for UI while 11% identified the need to administer pain medication for those with UI. Within the hospital context, it can be argued that these two interventions are reasonable. The increase in the length of oxygen tubing likely enabled patients with UI to travel effectively to the bathroom away from the bedside oxygen delivery system. The rationale for pain medication is that it maximized comfort and mobility to facilitate toileting activities. The referent practice guidelines (Fantl et al., 1996) were not developed with findings from studies in hospital settings, nor were there any identified intervention studies for UI in hospital

settings at that time. At the present time, there are no published studies that examine UI guideline implementation in US hospitals.

Perhaps, the failure to implement UI clinical guidelines may be because the institutional goal(s) of UI care do not focus on the individual needs of older adults, but rather, serves to meet the processes of particular care settings. For example, nursing home residents exhibited behaviors from a set of six strategies to manage UI, or the potential for UI (Robinson, 2000), two of which were “letting it [urine] go” or “speaking up.” These strategies were influenced, in part, by the support received from nursing home staff. Anecdotal evidence from the investigator’s clinical hospital practice suggests that hospitalized older adults do not want to “bother” the “very busy” nurses. Their strategy is to either “hold in” the urine, or “just let it out.” UI may not be a priority for the hospitalized patient or the staff because alterations in health are more immediate and frequently life-threatening.

In sum, UI assessment appears to be a haphazard process. It is unclear how the assessment process influences the treatment plan and outcome. It is not known how the assessment and treatment of UI, specifically new-onset UI, occurs in hospitals. No intervention studies were found that specifically addressed new-onset UI.

Factors that influence UI care. Embedded in the literature are several factors that appear to influence how UI is conceptualized and how clinical guidelines are applied in practice: beliefs, knowledge, environment, and motivation. However, no literature was found about the degree to which each of these factors influences how UI is addressed. The following discussion suggests how each factor influences conceptualization of UI and UI care.

Beliefs. Three studies described two conflicting beliefs about incontinence (Cartier, 2003; Jervis, 2001; Mitteness & Barker, 1995). One belief is that incontinence is a normal consequence of aging; and the second is that incontinence is not normal and is treatable. The first belief prevailed among groups of South Asian Indian women and community-dwelling older adults in the U. S., often confirmed by health care professionals (Doshani, Pitchforth, Mayne, & Tincello, 2007; Palmer & Newman, 2006). Nursing assistants in nursing homes in the US also believed that UI was normal for older people (Mather & Bakas, 2002), as did hospital nursing staff; that is, that UI is an inevitable consequence of aging (Dingwall & McLafferty, 2006). This belief is linked to care strategies directed at containment and concealment of UI (Cartier 2003; Doshani et al., 2007; Mather & Bakas, 2002; Mitteness & Barker, 1995). The belief that UI is not normal is noted in gerontological nursing and medical literature (Dowling-Castronovo & Bradway, 2008; Specht, 2005; Wagg et al., 2005). Yet, no study of patient perspectives was found to support this belief.

Conflicted beliefs were identified within the nursing hierarchy (Cartier, 2003). Low wage nursing assistants in hospitals and nursing homes performed “custodial” care with containment and concealment strategies whereas high wage nurse specialists enlisted sophisticated care strategies, such as biofeedback-enhanced PFME (Cartier, 2003). A survey conducted to understand the influence of federal (US) regulations designed to improve care for UI in nursing homes found that nursing home administrators felt that the regulations were unrealistic, and nursing staff worried about the effects of the regulations on residents rights (DuBeau et al., 2007). An example of shared concerns was that performing post-void urine residuals in accord with regulations disrupted efforts to

create a home-like setting; thus, federal regulations would not promote resident quality of life. It is not understood whether and/or how these beliefs influenced UI assessment and care.

Conflicted beliefs about care for UI are held by care providers trying to cope with UI. In an ethnographic study of nursing homes, Jervis (2001) found that professional nurses relegated care for UI to nursing assistants, who were forced to independently and silently learn how to perform this care, a fundamental aspect of their job. Despite initial and persistent feelings of repugnance, nursing assistants emphasized “their more culturally valued role as helpers” (p. 93). Repeated exposure to UI desensitized the nursing assistants who then developed a series of strategies to reinterpret and give meaning to incontinence care. This, in turn, allowed nursing assistants to contend with care for the person with UI while retaining their own self-respect.

Specific to hospitals, there was a striking difference between professional nursing staff and medical staff in that 37% and 4% believed, respectively, that hospitalized older adults who experienced UI did so to seek attention (Fonda & Nickless, 1987). Dingwall and McLafferty (2006) found that hospital nursing staff believed patients accepted UI as part of the aging process, hid their UI, and used self-help strategies rather than seek professional assistance. They also believed that the longer the older adult experienced UI, the more they accepted it.

In sum, care for UI is likely influenced by many different beliefs, some of which are in conflict with each other. No studies were found that specifically addressed professional or patient beliefs about new-onset UI. However, analysis of the literature and findings of this study suggest that a “window of opportunity” for intervention may exist.

Knowledge. Physicians and nurses have inadequate knowledge about clinical guidelines for UI (See Appendix A). This is likely the result of a basic education that fails to adequately prepare them to apply clinical guidelines. Almost three-fourths of general nurse practitioners in New Zealand reported no undergraduate training in assessment and treatment of UI (Dovey et al., 1996). Although Educational Continence-Care Competencies derived from a multi-phased consensus process exist for nursing education in the US (Jirovec et al., 1998), the extent to which these have been incorporated into education is unknown. In nursing homes in Canada, nurses and nursing assistants described inadequate knowledge about evidence-based assessment and treatment for UI as a barrier to providing optimal care (Tannenbaum et al., 2004). There were significant differences between nursing home staff and government surveyors in their basic knowledge about revised federal nursing home regulations for the assessment and treatment of UI (DuBeau et al., 2007).

Specific to hospitals, nurses generally lacked the knowledge needed to assess and care for UI in accord with clinical guidelines (Cooper & Watt, 2003; Hancock et al., 1996). Less than 40% of hospital nurses (n=150) respondents correctly understood the causes of urge and stress incontinence (Hancock et al., 1996). In another study, hospital nurses knew urinary frequency with UI was a sign of a UTI for an older adult, but they were not knowledgeable about post-prostatectomy UI or overflow UI associated with diabetic neuropathy (Cooper & Watt, 2003).

It is unclear how knowledge about clinical guidelines influences care practices. A survey of 208 hospital nurses identified significant differences in knowledge between staff who attended a workshop (46%) about UI compared to those who did not attend

(Connor & Kooker, 1996). Attendees reported significantly more attempts to practice the interventions taught at the workshop and perceived these to be at least 50% effective.

Yet, the degree to which practice did in fact change is unknown. Williams and colleagues (1997) tested the effectiveness of a clinical handbook for UI. Although there was a significant improvement in post-test knowledge scores for the group that received the handbook, it was not known how this affected care. Despite the availability of informational brochures about UI, staff in rehabilitation units did not use this resource to educate patients (Coffey et al., 2007).

In sum, although knowledge likely influences care practices for UI it is unclear to what extent. Studies to date have reported what health care providers have “said” about addressing UI. What is known is poorly translated into practice settings. No studies about knowledge of new-onset UI were identified.

Environment. Care for UI is influenced by the context, that is, policy, pollution, social processes, and institutional characteristics. From a policy perspective, continence specialist nurses in the US described health care policies that negatively influenced how care for UI was addressed (Jacobs, Wyman, Rowell, & Smith, 1998). Care performed in accordance with clinical guidelines was not reimbursed and advanced practice nurses were prohibited from prescribing needed pharmacological therapies. The degree to which policies have changed since this study was conducted is unknown. Although Centers for Medicare and Medicaid Services (Department of Health and Human Services, 2005) revised the survey of UI in nursing homes, the extent to which care has been influenced has not been documented.

It is not clear how health care policies and clinical guidelines address a common theme that was noted in the literature (Cartier, 2003; Jervis, 2001; Mitteness & Barker, 1995); that is, care for UI is performed to prevent pollution, “matter out of place” (Douglas, 1966). Mitteness and Barker (1995) found that community-dwelling older adults used containment and concealment strategies, the most extreme being social isolation, to control the environment and maintain the façade that urine was in its proper place. Findings suggest that older adults who fail to adequately care for their UI in accord with standards of where they live and prevailing social norms and processes pollute the environment. As a consequence, they burdened their informal caregivers; were labeled incompetent; were evicted from independent living communities; and needed more assistance with care in assisted living facilities (Cartier, 2003; Mitteness & Barker, 1995). These findings suggested that UI is not as acceptable in the community as it may be in an institution where the “pollution” of incontinence is more prevalent (Jervis, 2001).

Institutional characteristics that influence care for UI included staffing, team work, availability of technology, such as bladder sonograms, and environmental support (Resnick et al., 2006; Tannenbaum et al., 2005). It has been well documented that care for UI is time consuming and requires adequate staffing (Dingwall & McLafferty, 2006; Johnson & Ouslander, 2006; McCormick, Scheve, & Leahy, 1988; Schnelle et al., 2002; Tannenbaum et al., 2005). Long-term care nurses reported that a ratio of one staff to six residents with UI is needed for optimal UI care to occur (Tannenbaum et al., 2005). While Schnelle and colleagues (2002) recommended a ratio of 1:5 to perform an exercise intervention that included prompted voiding, pad changes, and an offering of fluid, all of

which required an average of 20.7 minutes per episode of care, these staffing ratios may not always be feasible.

Lack of teamwork, such as inconsistent cooperation from team members, hindered care for incontinence in several studies (Mather & Bakas, 2002; Resnick et al., 2006; Rodriguez et al., 2007; Tannenbaum et al., 2004), including one in acute care (Nikoletti et al., 2004). Of particular note in one study, directors of nursing (DONs) recommended a team approach for toileting activities yet recommended rewards only for those nursing assistants (NAs) who demonstrated good care, specifically toileting residents (Resnick et al., 2006). This reward seems counterproductive with their recommendation for teamwork. Although debatable, it seems that the DONs believed toileting activities to be the sole responsibility, a hallmark of, the NA's role.

Whether and how the physical environment influences care for UI has yet to be described explicitly. Nurse managers reported that adequate toilet facilities promoted continence in two rehabilitation units in Ireland (Coffey et al., 2007). Location of toilets was a barrier to continence in a rehabilitation unit in an Australian hospital (Ostaszewicz, 2006). Lack of physical space in general practitioner offices was a barrier for nurse assessment and care for patients with UI (Byles et al., 2005). In nursing homes, NAs identified that care for UI would be improved if the environment facilitated function (Resnick et al., 2006). Specifically, these NAs identified the need for safe and comfortable toilets. Despite these findings, no study detailed the continence-promoting characteristics of the physical environment.

In sum, care for UI appears to be influenced by the environment, but the extent to which the environment does this is unclear. No studies that adequately examined how UI

is addressed within the hospital were found. Findings from this study begin to explain how institutional characteristics of the hospital, specifically the routines of hospital workers influence bladder control.

Motivation. The role of motivation on part of patients and providers is underdeveloped in the literature. Patient motivation to perform care consistent with guidelines was briefly mentioned in two of three case studies (Beheshti & Fonteyn, 1998). A focus-group study that included 81 community dwelling older adults the majority of which were Black found that will power and an understanding of the consequences of UI were motivating (Palmer & Newman, 2006). Long-term care nursing staff – nurses, NAs, and orderlies - described that residents needed to be motivated in order to provide care consistent with clinical guidelines (Tannenbaum et al., 2005). Interestingly, patients who used Australian National Continence Services described the need to be persistent while seeking care for UI, yet the reason for this was unexplained (St. John et al., 2002). No studies were identified that explicitly addressed motivation on the part of the health care provider.

One nursing home study examined how staff implemented scheduled toileting (Schnelle et al., 2003). The researchers found that residents with documentation of toileting schedules were significantly less cognitively and physically impaired in comparison to those without toileting documentation. Interestingly, residents who required no human assistance received significantly more assistance to toilet than did residents who did require human assistance (Schnelle et al., 2003). Perhaps higher functioning residents and staff motivated and responded to each other by creating a positive feedback loop that fostered toileting activities.

In hospitals, nurses felt hopeless about caring for or curing UI (Cooper & Watt, 2003; Dingwall & McLafferty, 2006). It may be that the demands of an acute care hospital unit took precedence over basic nursing care. As a result, UI care met the needs of the unit routine rather than the needs of individual patients. In turn, it is likely that hospital nurses may not be motivated to perform care to alleviate UI.

In sum, the role that motivation plays in the care for UI has not been well-studied. Studies of the role of motivation for the care of new-onset UI were not found. Findings from this study include the main concern that motivated participants.

New-Onset UI – A Professional Nursing Problem

Analysis of the literature suggests that nurses are the primary providers of UI care. Typically, individuals turn to physicians with health care problems, who by and large fail to perform screening for UI; do not demonstrate interest in managing UI; fail to offer holistic treatment; do not possess knowledge of evidence-based assessment and treatment of UI; and refer to nursing for management (Cochran, 2000; Jeter & Wagner, 1990; Starter & Libow, 1985; Miller et al., 2003; Mitteness, 1987a, 1987b; Palmer & Newman, 2006). It has been suggested that nurses are able to create an environment that temporarily suspends stigma to allow for effective assessment and treatment of incontinence (Norton, 2006; Palmer & Newman, 2006; St. John et al., 2002; Twigg, 2006), and that a nurse “continence champion” is needed to implement UI practice guidelines in hospital settings (Ostaszkievicz, 2006). In the community, nurse-led protocols have resulted in improved outcomes for community-dwelling individuals with UI (Beheshti & Fonteyn, 1998; Dougherty et al., 1998). Byles and colleagues (2005) evaluated three demonstration projects of community-wide continence care services in Australia. Only

the nurse-led model demonstrated a significant decrease in the severity and the problematic nature of UI.

However, there are varied findings about how nurses view UI as part of professional nurse work. One study revealed that hospital nurses do not view UI as a nursing issue (Cooper & Watt, 2003), while another (Dingwall & Mclafferty, 2006) found that assessment of UI was viewed exclusively as a nursing role, but treatment was not. These findings may explain why new-onset UI has been under-addressed. Nevertheless, given the incidence and prevalence of UI in hospitals together with the fact that UI is associated with falls in hospital (Krauss et al., 2005) and is a nursing-sensitive indicator of quality care (Montalvo, 2007), UI is (or should be) a professional nursing problem (Glaser, 1998).

In the hospital setting, new-onset UI seems modifiable to nursing intervention. It is known that depression, malnutrition, and dependent ambulation are risk factors for new-onset UI (Kresevic, 1997). However, there were no intervention studies identified. Review and analysis of the general UI literature suggests that more information is needed before designing an intervention study for new-onset UI of hospitalized older adults. In particular, there were no studies that explained the main concern (Glaser, 1998) of hospitalized older adults who experienced new-onset UI and how they addressed this concern. Findings from this study provide a substantive theory to understand how hospitalized older adults with new-onset UI behave.

Summary

Review and analysis of this literature demonstrated that new-onset UI is a professional nursing problem that has received little scientific attention. In order to hypothesize

the future direction for research and practice regarding assessment and treatment of new-onset UI, it was essential to inductively study. Findings of this study describe the main concern of hospitalized older adults with new-onset UI and explain how they worked to resolve that concern.

Research Question

It was essential to let the main concern of the participants emerge (Glaser, 1998; Glaser & Strauss, 1967). The initial question that guided this study was: What is it like for older adults to start having trouble with bladder control in the hospital?

Chapter Three

Method

New-onset UI has not been the subject of very much scientific investigation. Grounded Theory (GT) methodology is a systematic research method for discovery of theory about human behavior in social settings (Glaser 1978; 1998; Glaser & Strauss, 1967). It is particularly well-suited for studies of behavior and social processes that have received little scientific attention as is the case of hospitalized older adults with new-onset UI (Glaser, 1978).

Grounded Theory includes constant comparative analysis, theoretical sampling, theoretical memos, and dynamic hypothesis formulation and re-formulation (Glaser & Strauss, 1967; Glaser 1978) all of which are described later in this chapter. The result is a theory that explains patterns of behavior by a group of individuals in a substantive area in response to a common concern. It calls for rigorous and continuous analysis of collected data, from which the principle investigator (PI) generates new questions that are grounded in, and guided by, the data. These new questions are used to re-query the data. The emerging theory is continuously refined.

This chapter describes the setting for the study, participant recruitment, procedure for protection of human subjects, and data sources and collection. Methods used for data collection, analysis, and a discussion of trustworthiness, or rigor, are also presented.

Description of the Setting

The focus population for this study was hospitalized older adults experiencing new-onset UI. Participants were recruited from an inpatient rehabilitation department within a 714-bed teaching hospital of an award-winning health care system serving a

north-eastern metropolitan area of the United States. Typical patient demographics for two inpatient rehabilitation units included: 71% 65 years of age or older; 58.7% female; over 85% English speaking; and, almost 90% admitted from other in-patient units. The average length of stay was 15.8 days with 63% of patients discharged to the community from which they were admitted. Primary admission diagnoses were stroke (19%), orthopedic (37.9%), and cardiac (3%) conditions.

Two inpatient units accommodated 63 patients. The first unit occupying a full hospital wing had three private (single bed) rooms and one three-bedded room. The remaining rooms were semi-private (2-bedded) that were occasionally utilized as private rooms as determined by management. The unit had a large day room with couches, four computer stations, a kitchenette, a large flat-screen television, and table. Books and board games were available for patients and their visitors. During the day, the room was used for structured group therapy activities, such as chair yoga, provided by the therapists; and feeding groups, typically consisting of several patients with dysphagia, were held during meal times. Weekly family orientation meetings provided refreshments. Scheduled recreational activities, such as arts-and-crafts, were posted on a on a dry-erase board calendar outside the entrance to the unit. The second unit was the front half of one hospital wing. With the exception of three private rooms, the remaining rooms were semi-private. Patients from these two units attended therapy sessions, along with patients from other hospital units, either in the rehabilitation gym or in the satellite gym.

Participant Recruitment

Inclusion and Exclusion Criteria

Participants met the following inclusion criteria: inpatients in the rehabilitation setting, age 65 years or older, able to verbally communicate in English, cognitively intact based on hospital record documentation, agreement to participate, continent - no sign or symptom of any amount of involuntary loss of urine - six months prior to hospitalization as reported by the patient. Also, they must have had at least one episode of UI - involuntary loss of any amount of urine - during hospitalization as reported by patient and/or hospital staff. Exclusion criteria: patients with indwelling urinary catheters at the time of recruitment were excluded.

Sampling Method

Initially, purposive sampling (Patton, 2002) was conducted. The PI, a nurse with extensive hospital experience, conducted field visits to the hospital and used the fieldwork strategy known as the “known sponsor approach” to gain entry to the setting (Patton, 2002, p. 312). The PI identified appropriate hospital sponsors to endorse the PI's legitimacy and credibility. Examples of these sponsors included the Chairman of Rehabilitation Services, the Institutional Review Board Manager, the Vice President of Rehabilitation Services, Attending Physicians, Nursing Unit Managers, and Nurse Practitioners (NPs). Negotiation for access to patients followed formal processes that included the identification of “key informants” (Patton, 2002, p. 321), such as the unit managers and NPs. Perspectives from these individuals provided nuances, such as unit culture and informal rules, that were only experienced by an emic insider (Patton, 2002, p. 267).

Sixty-one field visits totaling almost 170 hours occurred from December 2009 to May 2012, which included the time the PI spent performing recruitment and interviews. During these field visits the PI observed the unit environment for physical structural characteristics, such as access to toilet. The PI explained the purpose of the study to relevant hospital staff, such as attending physicians, nurse managers, staff nurses and therapists, and identified licensed nurses who were willing to assist in recruitment. Observations and interactions from these field visits were captured in field notes.

The two inpatient rehabilitation units had one nurse manager, three assistant nurse managers, 51 staff nurses (full time/part time) and 47 nursing assistants. The PI met with all four nurse managers to explain the study, specifically the need for interested nurses to assist with recruitment of patients. For this purpose, the PI prepared a one-page information sheet and flyers (see Appendix D and E) that was disseminated by the chief nurse manager during a staff meeting. The flyers were placed in a central location for patients, staff, and visitors to view. Two NPs became the unit-based “champions” who screened the census for patients who met three of the inclusion criteria: age, cognitive status, and ability to speak English. If a patient met those three criteria, then the NP obtained their permission to introduce the PI.

After the NP received permission from the patient (hereafter, referred to as the “potential participant”) the PI met the potential participant at their convenience to explain the study and determine the status of the other eligibility criteria. Typically, this meeting occurred within minutes after he or she gave permission to the NP. Occasionally, the potential participant preferred to have the PI come at another time, such as a weekend or holiday when they did not have therapy sessions. Each recruitment encounter with a po-

tential participant, began and ended with the PI asking, “Is there anything that I can do or get for you; or, have the staff do or get for you?” These potential participants often asked for basic assistance, such as making sure needed objects (call bells, phones, tissues, etc.) were within their reach. At this time, the PI provided information about self and the study. This informational discussion included ascertaining if the potential participant had experienced new-onset UI. If yes, then the PI asked the potential participant if (s)he was willing to participate in the study while emphasizing the voluntary nature of participation. If the potential participant refused to participate, the reason for refusal was solicited and written in field notes. If the potential participant agreed to participate in the study, then he or she was given the consent form (See Appendix F) to read, or the PI read it to the participant. Time was provided for any questions and concerns from the participant, which the PI addressed. On four occasions the consent was left with potential participants at their request to have more time to think about participation of which two did consent to participate. After consent was obtained, the interview was scheduled according to the participant’s preference (n=14). Demographic data (See Appendix G) was collected from the hospital record and verified with the participant. At the request of three participants, three interviews occurred after their discharge from the hospital: two interviews were conducted in private homes; one was conducted in a long-term care facility. Seven interviews were conducted immediately after signing the consent. The other four interviews occurred on a weekend/holiday a few days after signing the consent. (See Appendix H for Summary of Participant Demographics).

Theoretical Sampling

Theoretical sampling is an iterative process done in close association with the “Constant Comparative Method” (described below). The investigator adjusts data collection to identify categories of emerging behavioral patterns. As this is done, the investigator repeatedly returns to the data to review and test it by comparing and contrasting incident to incident, and incident to emerging categories. The incident, or indicator, is the unit of analysis. Incidents come from data that consists of notes from new sources as well as notes and memos from previously coded and sorted sources, such as interview transcripts. Glaser (1978, 1998) asserted that there is no *a priori* “n” in grounded theory studies. One interview may provide many indicators, or n’s of data, for analysis. For this study theoretical sampling continued until theoretical saturation, that is, the point at which sampling and analysis ceased to identify new incidents and categories (Glaser 1978, 1998; Glaser & Strauss, 1967).

The PI initially used an interview guide (see Appendix I) and through simultaneous data collection and analysis, or the Constant Comparative Method, purposive sampling transitioned to theoretical sampling as directed by the developing theory (Glaser 1978, 1998; Glaser & Straus, 1967). Specifically, tentative theoretical relationships directed the querying of the data. For example, a theoretical relationship that emerged was: participants conformed to institutional care in order to address their main concern which was to regain enough physical control to go home. Therefore, the PI re-questioned the data and asked subsequent interviewees (See Appendix J for how the guided questionnaire evolved) about conforming. This supported and refined the label for the category, related categories, properties, and theoretical relationships.

There was emergence of an initial working core category, conforming to institutional routines/care, as early as coding and comparison of the sixth interview (see Appendix K – Examples of Coding and Theoretical Memoing). At this point, purposive sampling most clearly transitioned to selective coding as directed by the developing theory (Glaser 1978, 1998; Glaser & Straus, 1967). This process of discovering a “best fit” label was consistent with GT methodology (Glaser, 1978, p. 94). The PI repeatedly reviewed new and previously collected data using inductive and deductive comparisons. Subsequent labels for these actions included: dealing with the establishment, working it, getting out, walking the line to get out. This was consistent with GT methodology that requires a “best fit” label be assigned when the investigator identifies a “main theme”, which explains how the participants try to solve their main concern, so that the investigator has a “...handle for thinking of them.” (Glaser, 1978, p. 94). When new data was collected it was analyzed for new categories and properties of categories and compared with existing ones to sort for prominence and fit. These comparisons modified the core category explaining how the participants worked to regain control.

Protection of Human Subjects

Approval of the study was obtained from the Institutional Review Boards at Rutgers, the State University of New Jersey and the site hospital. All participants were informed by the PI about the purpose and goals of the study, risks and benefits, and given time for questions or concerns all of which were addressed by the PI. The process for consent is detailed above.

The ethical PI must maintain awareness that hospitalized older adults may be frail and fatigue easily. Therefore, during each PI-participant interaction the PI continually

assessed and evaluated if the participant experienced fatigue or distress. This was consistent with recommendations made by Kresevic (1997) and Koch (2006) that data collection be conducted by individuals with experience in direct patient care to benefit both the accuracy of data collection and maintain patient safety. For example, during one interview the PI, having noted non-verbal facial grimacing consistent with pain, reminded the participant she was free to stop the interview for any reason. The participant wanted to “press on”, but the PI determined that the participant was becoming fatigued. The PI decided to end the interview and immediately notified the staff nurse.

The focus of this study, UI, is a stigmatized topic (Norton, 2003) and may have generated feelings of embarrassment among participants. This risk was addressed in the consent form. However, Norton (2006) reported that individuals with UI welcome the opportunity to discuss their experiences and that the nurse is best positioned to suspend social stigma (during disclosure) so that full discourse can occur. It has also been suggested that responsive interviewing, one that asks for narrative, leaves participants feeling rewarded (Rubin & Rubin, 2005). Interviews have been reported to be healing (Patton, 2002); and some people participate in interviews to be altruistic (Rubin & Rubin, 2005). These documented benefits of participation were noted in this study. For example, one participant expressed altruism when verbalizing that being a part of the study would be “helping” the PI to complete the study and verbalized hope that the study would help future hospitalized older adults. Another participant, who died several weeks after discharge from the hospital, told his wife about how he enjoyed the interview interaction; she shared this with the PI.

To minimize the risk of disclosing participants' identity, each participant was assigned a code that was used on all data collection documents (described below). Flash drive and paper versions of data documents, were placed, and remained, in a locked file cabinet accessible only by the PI and will be destroyed three years after completion of the study. Consistent with GT methodology the purpose was to conceptualize the behaviors of the participants and not provide descriptive narratives that may be identifiable. In this dissertation, and in any subsequent dissemination of findings, illustrations of data are devoid of identifying information.

Data Sources and Collection

Data sources for the study included 61 field visits to the inpatient rehabilitation unit from December 2009 to May 2012, interviews with 14 consenting participants, and their medical records. The PI collected data using field notes, a Demographic Data Sheet, and audio recorded semi-structured interviews with the participants. The PI wrote notes of field visits, interviews, and phone calls. In sum, over 4,260 lines of data were collected.

Data from almost 170 hours of field visits were documented in field notes, of which most took place from 8:30AM to 5PM. This was the time that the majority of patient and unit activity occurred. The PI spent approximately 25 hours from 5PM to 8PM, and, from 5AM to 8:30 AM to gain the broadest perspective of the milieu. During field visits the PI participated in unit rounds with the interdisciplinary team, attended ad hoc staff in-services, meetings, and observed physical therapy sessions.

During field visits, spontaneously shared details from the participants and their behaviors were written in field notes. These details influenced how the audio-recorded

interview occurred. For example, the PI observed an interaction between a participant and a physical therapist. The participant appeared angry as evidenced by a heated tone of voice and closed off body language. The interview was conducted a short while after that observed interaction. The PI referenced the observed behavior. This then elicited interview data to confirm that the participant was, in fact, angry.

Using the Demographic Data Sheet (See Appendix G) the PI collected data about age, gender, ethnic origin, marital status, educational level, occupation and employment status, annual income, home environment, medical conditions, surgical history, medications, and hospital environment, such as access to and the condition of bathroom facilities. Hospital records were reviewed for information about new-onset UI, such as those documented on care plans, flow sheets, and admission, progress, and discharge notes. (See Appendix H for Summary of Demographics and Description of Episodes of new-onset UI.)

To avoid disruption of usual hospital routines, the PI conducted the interview outside of therapy schedules and visiting hours and according to the preference of the participant. Three of the 14 interviews were not recorded. Two of the three interviews were not audio-recorded due to lack of privacy and the noise in the environment. These interviews were not recorded to avoid the risk of recording voices of non-consenting individuals. For the third, a participant did not consent to recording. The PI wrote more detailed field notes during these interviews than during audio-recorded interviews. The PI used interview guides (Appendix I and J). The length of time for interviews ranged 35 minutes to 75 minutes. Audio-recorded interviews (n=11) were manually transcribed verbatim by the PI. Details from phone conversations, which occurred with some partici-

pants or their family members when the PI made phone calls to arrange interview appointments or clarify previously collected data, were written in field notes.

Data Analysis

The atlas.ti® program was used to assist with data management. Data collection and analysis occurred as specified by the constant comparative method (Glaser, 1978, 1998; Glaser & Strauss, 1967). To adhere to GT methodology, the PI extensively studied GT books, participated in peer group discussions, attended two GT seminars led by Barney Glaser, PhD, and consulted with a GT fellow (Tina Johnson, PhD). Constant comparative analyses of data, operational memos, theoretical memos, and multiple versions of the theory took place, which included interaction with dissertation chairs and aforementioned GT experts for about one year after the last interview was completed.

Constant Comparative Method

Done in close association with theoretical sampling, the constant comparative method for data analysis is another hallmark of GT methodology (Glaser, 1978, 1998; Glaser & Strauss, 1967). This method consists of two analytic procedures: 1) “making of constant comparisons of incident to incident, and then when concepts emerge, incident to concept, which is how properties of categories are generated”; and, 2) “asking the neutral, coding questions”, such as “what category or property of a category does this incident indicate?” (Glaser, 1992, p. 39). The PI analyzes the data to identify the common main concern of participants and how they go about resolving it. Initially, interview transcripts, demographic data, and field notes were constantly compared by substantive open coding that required line-by-line analysis of the data through constant comparison of incident to

incident, and, then, incident to categories compared to other incidents, and categories to other categories.

As categories emerged they were initially labeled using words from the participants and then, with additional data collection and analysis, more conceptual labels were generated. For example, the substantive code after line-by-line coding was initially “institutional routines” labeled to incidents, such as, “I get up so early at 5:30”; and, “I do all the exercises and everything that they [hospital staff] want me to do” (see also: Appendix K – Examples of Coding and Theoretical Memoing). Refinement of code labels occurred during subsequent analysis and conceptualization, which changed these to ‘Loss of Control’ and ‘Following Orders,’ respectively. This is consistent with the constant comparative analysis that uses working theoretical codes until a best fit label is discovered (Glaser, 1978). These theoretical codes emerged from following another essential feature of the constant comparative method: memoing.

Memoing. Theoretical memos guide theoretical sampling. Theoretical memos reflexively capture the “frontier of the analyst’s thinking” (Glaser, 1978, p. 83) in the PI’s conscious effort to move from the descriptive to the theoretical level. Emerging concepts direct theoretical sampling. Data were compared to the concepts so that properties of the concept, grounded by data, developed fully. Theoretical memoing (Appendix K) captured the relationships of the emerging concepts through theoretical coding, which conceptualized the potential relationships of substantive codes. During the process of working with GT experts and dissertation chairs, the PI became more mindful and wary of favorite codes, concepts, and theories. GT methodology is driven by discovery and not by forcing

data into *a priori* categories (Glaser & Strauss, 1967; Glaser, 1978, 1998). Specifically, the PI was mindful to let the main concern of the participants emerge.

Theoretical memos were analyzed and theoretically sorted (Glaser 1978). Theoretical memos were cut into solo units to manually sort to identify theoretical relationships (Glaser, 1978; Glaser & Strauss, 1967). Through the constant iterative comparison of incidents, categories, and relationships among the categories, the PI remained vigilant to identify the emerging core category (Glaser & Strauss, 1967; Glaser, 1978, 1998). The core category is a concept or basic social process that is central to the main concern of the participants. The core category must occur frequently, relate to other categories, and account for a large amount of the participants' behavior that addresses how they work to resolve, even if not resolved, their main concern (Glaser, 1978). Once a working core category was defined then the PI delimited and selectively coded data to identify related categories and properties and the conditions that influenced the behavior of the participants (Glaser, 1978). Operational memoing (Strauss & Corbin, 1990) consisted of procedural and reflexive notations made during the study. These procedural-related notations included data collection concerns, leads to pursue, sampling issues, and ethical concerns.

Trustworthiness/Issues of Rigor

The trustworthiness of a GT theory is its accuracy of fit, relevance, workability, and modifiability (Glaser & Strauss, 1967). Fit emerges from data, not data forced into theoretical categories (Glaser & Strauss, 1967). Fit indicates validity, which means that the label for a category or its property "fits the data" (Glaser, 1998, p. 140). "Relevance" is that a theory "deals with the main concern of the participants involved" (Glaser, 1998, p. 18). "Workability" demonstrates that the theoretical connections adequately account

for how participants address their main concern (Glaser, 1998, p. 18). In this study fit was achieved because the theoretical findings represent the data collected and relevance is achieved because the concerns of the participants should be relevant to health care providers working in hospitals. Last, the findings are open to being modified (Glaser, 1998). An expanded discussion of fit, relevance, workability, and modifiability is in Chapter Six.

Summary

This chapter detailed the setting, procedures for recruitment, protection of human subjects, and data sources and collection procedures in accord with Grounded Theory methodology. All Grounded Theory procedures to achieve trustworthiness were followed in the effort to study new-onset UI from how hospitalized older adults with new-onset UI, the focus population for this study, constantly worked to resolve their main concern.

Chapter Four

Description and Discussion of Theory

With the use of Grounded Theory Methodology (Glaser, 1978; 1992; 1998; 2002; Glaser & Strauss, 1967) the principle investigator of this study found that new-onset UI was not the main concern of the participants in this sample. Instead, in sharing their experiences with new-onset UI, participants revealed that their main concern was loss of control. By analyzing how participants dealt with this concern the substantive theory of Regaining Control emerged.

In response to an illness or injury that triggered biological damage or changes and loss of control, the participants in this study, hospitalized older adults with new-onset UI, worked towards Regaining Control by Transferring Control, Exercising “Wobbly” Control, and Adjusting to the Degree of Control Regained. Regaining Control describes and explains how participants “process [their] social or social psychological problem from the point of view of continuing social organization. [This is] irrespective of whether it solves the problem to some degree, it processes it” (Glaser, 1978, p. 97). Notably, with the use of GT methodology participants discussed and demonstrated their responses to episodes of loss of bladder control as a part of a much broader concern: loss of physical, spatial-temporal, and social aspects of control. Loss of physical control resulted in loss of spatial-temporal and social control that required hospitalization, which, in turn, contributed to loss of spatial-temporal control and a loss of social control as participants became dependent on others for assistance in a regimented environment.

Main Concern: Loss of Control

Before, during, and after hospitalization, participants are concerned with loss of control. Loss of control has three aspects: physical, spatial-temporal, and social. Loss of control is triggered by an illness or injury, such as a stroke, heart attack, orthopedic condition, or cancer that damages the body's biological capability. Depending on the extent of biological damage participants gradually or abruptly lose the biological capability to physically direct and regulate their bodies to perform routines of everyday living. These routines are dependent upon physical control, or voluntary functions of the physical body, which depends upon biological capability, in order to enact choices about how and where they spend their day and with whom they spend it. Spatial-temporal control refers to how participants manage the space around them and the timing of their actions. Social control is their management of social happenings, how they behave and interact with other people.

Physical control can be lost gradually or abruptly depending on the circumstances surrounding an illness or injury. Planned hospitalizations to treat gradual losses of physical control require participants to rearrange responsibilities of their daily life roles and change socialization patterns, leading to gradual losses of spatial-temporal and social aspects of control. These changes include going in for lab work, rearranging meeting or appointments or as one participant described, attending a patient education class. The result is a series of relatively gradual changes in daily routines. Over the course of four months one participant arranged [*Field notes*]: *time off from work* to perform a series of physician visits, pre-operative preparations that included a required patient education class to which she reluctantly attended:

They [hospital workers] even had me go to a class. I said, 'I am on a need to know basis'. I do not want to see a bed full of equipment – what you're going to do to me.' 'Oh no, you have to see this. We [hospital workers] are going to do this and this.'

In comparison, other participants, such as those who suffered strokes, experienced more abrupt changes in daily routines:

[Field note]: [Stroke] happened in his sleep. Participant awoke on a Monday morning with slurred speech and face decreased tone on one side. Couldn't form sentence. Pronunciation off. Friend said, 'Hospital.' Participant fought it and then agreed.

Loss of physical control ranges in degrees of impairment based upon the extent to which biological capability is damaged. Unless the rate and extent of biological damage renders one near complete physical incapacitation, participants are concerned about getting through their usual daily routines (spatial-temporal and social aspects of control), such as *babysitting for grandchildren [Field notes]*. When participants, or a trusted individual, such as a family member, come to the realization that the participant cannot independently manage what is causing their loss of physical control, and its resultant disruption of usual daily living activities, they are forced to get hospital care. Depending upon the timing of transition into the hospital they may have time to plan for consulting and transferring control of personal responsibilities to others, such as having friends or family provide them with help *[Field note]: daughter took participant to pre-admission testing and classes to help and also learn how to help the participant after surgery*. Other participants have family members who take on some of the daily routines for participants

without being asked: *my daughter took fish to her house – they're in safe care*. Participants may also worry about burdening these family members: *they have their own lives to live*.

Once in the hospital and throughout hospitalization, participants remain concerned about their loss of control. They primarily associate symptomatic physical losses of control, such as the inability to walk independently and loss of urine control, with the illness or injury that initially caused their hospitalization:

When the stroke came, everything fell apart. Like I said, they [children] took me to emergency. I couldn't hold my urine; I couldn't hold my bowel movements - for about two days. Then they [hospital workers] gave me so much medicine - ended up throwing up. I was sick as a dog. I kept saying I don't want any more medicine, but that's what happened to me. It was very uncomfortable.

Hospitalization further contributes to two other aspects of loss of control: spatial-temporal and social. No longer in their home and other familiar spaces, participants must follow rules, schedules, and procedures dictated to them by hospital workers. Staying in this complex controlled setting designed to service many patients, participants lose spatial-temporal control when they are told where and when to sleep, to eat, go to therapy appointments, and diagnostic tests. These actions restrict patient control and are considered by participants to be at the very least *annoying*:

- *I get up so early at 5:30 AM*
- *They [hospital workers] changed my room three times which annoyed me.*
- *[Field notes]: One participant commented, meal tray late; another, not what I ordered when meal tray was delivered.*

In this role as the patient, participants also lose control of how and when they are able to interact with family and friends:

- *[Field notes]: Visiting hours 4 PM to 8 PM or at the discretion of the hospital staff.*

Participants must temporarily live and interact among people not of their choosing - other patients and hospital workers. Some participants expressed concern about the unfamiliarity of hospital surroundings: *never know what is going on out there [outside of the patient's room], such as when something happens and they [hospital workers] shut the doors. You don't know if someone died, or what.* Not able to control these social happenings, participants worry about bothering hospital workers who are busy caring for many patients. One participant commented: *They have so many to deal with, that's why, they become overwhelmed;* and another participant: *They are so busy. They are doing things for me. The bells are ringing. They have to go into another room. Patients are hanging [pause] sitting on the toilet, waiting.*

When uncertain that loss of physical control is temporary, participants worry that loss of control will be permanent and result in losing control of their usual ways of living. The following participant wanted to return home with a live-in aide, not to another institutional healthcare facility. Field notes prior to the interview recorded that this participant walked in therapy. Yet, during the interview she expressed concerns about perceived confusion about returning home:

Just the idea that I'm here and I want to walk. And I go downstairs [gym]. I do all the exercises and everything that they want me to do. But now I have to ask my doctor where am I going after I leave here: am I going to go home to my house or am I going to go to the other place? Because they said I'm going to go over to the

other hospital [nursing home] rehabilitation. And I said why would I be going there if I'm okay to go home. You know?

This participant was concerned that she seemed to have little control over her post-hospital placement. Field notes after the audio-recorded interview captured this same participant's concern about the possibility of being permanently placed in a nursing home.

Ultimately participants want to get out of the hospital and go home and not to a long-term care (LTC) facility. A participant summed her concerns when she said: *[I want to] get out of here. Be independent – able to do for myself.* Participants worry that their loss of physical control may become permanent lost control: *I think the thing that would concern me is if I couldn't walk.* Participants want to return to and regain spatial-temporal and social aspects of control similar to their pre-hospital living: *[I want to] Get back to my golf and enjoy the rest of my life.* These participants work to regain the three aspects of control.

Regaining Control

Regaining Control is a complex, iterative and overlapping three-phase process:

Abridged Overview of Regaining Control (See Appendix L for Full Overview).

Phase	Transferring Control	Exercising “Wobbly” Control	Adjusting to Degree of Control Regained
Definition	Active or passive handing over of control to provisional controllers	Unsteady progressive and iterative exertions of control that fluctuate and may, or may not, regain control with each effort.	Acclimating to the extent of control regained
Timing/ Onset	Pre-hospitalization New or recurrent loss of biological capability due to biological damage	Begins with biological recuperation	Begins when biological recuperation plateaus
Properties	Consulting Submitting	Learning Following orders Directing Provisional Controllers Resisting Concealing	Reminiscing Reassigning control Leaving the institutionalized patient behind

Transferring Control begins in response to an onset of illness or injury that has damaged biological capability. This causes a loss of physical control and a subsequent effect upon spatial-temporal and social aspects of control. Influenced by their understandings of hospitals, participants actively or passively hand over varied aspects and degrees of control to two groups of provisional controllers who then provide supplemental control or conditional support. This supplemental control may or may not offset the aspects and degrees of loss of control for the participant. The two groups of provisional controllers are informal and formal. Informal provisional controllers are trusted individuals, such as spouses, significant others, family, or friends, many of whom become informal caregivers. The second group, formal provisional controllers, consists of emergency responders

and hospital workers, professional and ancillary. Transferring Control has two properties: consulting and submitting.

The second phase, Exercising “Wobbly” Control, is triggered and influenced by biological recuperation, an involuntary and not completely predictable return of biological capability varying in degrees. Biological recuperation prompts participants, who are Exercising “Wobbly” Control, to work to regain more physical, spatial-temporal, and social aspects of control with unsteady and iterative exertions of fluctuating control. Participants begin to attempt physical, spatial-temporal, and social actions and reactions to practice skills, such as walking and stair climbing with the use of assistive devices, needed to regain control. Each exertion of Exercising “Wobbly” Control may, or may not, result in regaining complete control with respect to any or all three aspects of control. Exercising “Wobbly” Control is strongly dependent upon biological recuperation. How and when a participant regains physical control is not consistent or completely predictable, but advances over time. This advancement in physical control facilitates advancement toward regaining spatial-temporal and social aspects of control. During this second phase of Regaining Control participants practice what can and must be done to satisfy themselves and those who must agree and validate (usually formal provisional controllers) that they have regained enough control, *to get the hell out of here [hospital]* and return home. Exercising “Wobbly” Control has five properties: learning, following orders, directing provisional controllers, resisting, and concealing.

The last of the three phases, Adjusting to Degree of Control Regained, begins when biological recuperation reaches a plateau. This biological recuperation plateau is identified by hospital workers who determine that the participant’s biological capability

has reached a level of physical control that no longer requires hospital care. Although, this does not necessarily mean that the participant's biological capability has fully returned to a pre-hospitalization level or to a level that enables them to return to their pre-hospital lives. During this phase participants must acclimate to the extent of control regained and prepare for life after hospitalization. They reflect upon past ways of dealing with losses in life to draw strength to accept current residual losses of control. Participants actively or passively reassign control for their residual physical, spatial-temporal, and social aspects of loss of control to informal or new formal provisional controllers. New formal provisional controllers may be from home care agencies or nursing homes. Finally, participants are discharged and try to forget having been a hospitalized patient. Adjusting to Degree of Control Regained has three properties: reminiscing, reassigning control, and leaving the institutionalized-patient behind.

Three conditions influence the progress and degree to which participants regain control: biological recuperation, understandings of hospitals, and provisional controllers. When a participant is incapacitated, their ability to exert any kind of physical control is challenging at best. With biological recuperation comes a greater desire, willingness, and capability to regain control. Participants have varying understandings of hospitals. These perspectives of hospitals stem from prior hospitalizations or experiences with hospitals and influence how they learn to behave during their current hospitalization. Finally, informal and formal provisional controllers provide supplemental control for participants as they work through the process of Regaining Control. Although not the focus of this Grounded Theory study these three conditions are notable as they influenced how participants worked to regain control. Explanations of how these conditions modify the process

of Regaining Control are presented after discussion of the three phases – Transferring Control, Exercising “Wobbly” Control, and Adjusting to Degree of Control Regained - and their related properties.

1) Transferring Control

Before entering the hospital, illness or injury causes biological damage and loss of physical control that triggers participants’ main concern, loss of control, and how they begin to respond to these losses. Participants’ initial reactions to the onset of loss of control are characterized by denial, refusal, doubt, or inability to recognize that hospitalization may be necessary.

When this [stroke] happened around 1 PM, I did not come in [to the hospital] until almost 5 PM because I did not listen to my girlfriend, you know, I could hear myself slur my words when she was asking me to make faces and squeeze her hands. I didn’t want to hear it.

Biological damage results in loss of physical control that leads to loss of spatial-temporal and social aspects of control. The outcome of this is inevitable for participants: a hospital admission. Transferring Control is an active or passive handing over of varied degrees and aspects of control to trusted individuals and hospital workers, who then become informal and formal provisional controllers providing supplemental control. This is done to maintain as much of the participant’s remaining aspects and degrees of control as possible and initiate treatment for biological damage. Some participants actively perform this transfer of control as was the case for one participant, who was an informal caregiver for her ill husband. She made arrangements for her daughter to temporarily be in charge of this care: *my daughter is taking care of my husband [with Alzheimer’s]*. Other partici-

pants continue to deny, refuse, doubt, fail to recognize, or are physically unable to transfer control. Some participants suffer severe debilitating biological damage rendering them physically incapacitated. One participant recalled thoughts during the ambulance ride after his wife called 911 in response to his stroke *[Field note]*: ‘*This can’t be happening.*’ In this instance passive transfer of control was needed and performed by both informal (his wife) and formal provisional controllers (ambulance paramedics). Transferring Control is initiated so that the participant’s biological damage can be limited through treatment for a period of time until biological recuperation begins and participants work to regain control. Dependent upon degree of biological recuperation this transferred control may or may not be fully regained. Transferring Control has two properties: consulting and submitting. Participants engage in these preliminary actions of Regaining Control to prevent a temporary loss of control from becoming permanent.

Consulting. Following initial loss of physical control caused by biological damage participants require advice about how to prevent further loss and regain control. Participants consult by actively seeking or passively receiving needed advice. Advice may be from informal sources, such as family or friends, or from formal sources, such as health care professionals. People from these sources become, to varying degrees, the participant’s provisional controllers. When physical loss of control results in progressive difficulty in completing daily routines, some participants actively seek advice from informal sources and then seek professional advice:

As I get ready to get off the bed, I feel funny. My head is numb – whole ground is a whirlpool and the walls are going around. I was like paralyzed. I couldn’t manage. How I did, believe me dear, I don’t know. I went to the bathroom and did

what I had to do. Then I went over to the telephone and called my daughter and said, 'Look I am calling up the ambulance, I don't feel good at all.' They [EMTs] came. They checked me over and said, 'We're going to have to take you to the hospital.'

Others who continue to deny, refuse, doubt, or are unable to recognize that loss of physical control and needs hospitalization, may have a provisional controller who recognizes it. This controller may take charge as a proxy by making decisions and taking actions once made by the participant: *When my daughter came that morning, I kept saying, 'I can't make the bed' and she would say, 'Mommy don't worry about that...you have to go to the hospital. You have to – we will get you there.'* Sometimes this firm advice, or pressure, from informal provisional controllers, is needed so the participant will consult with formal provisional controllers, such as emergency responders or a physician. This provisional controller-supplied supplemental control is needed by participants who are unable to independently address biological damage and resultant loss of control.

The timeline from initial illness or injury to informal and formal consulting to hospitalization depends upon the degree of biological damage, its affect on physical control and the subsequent influence on the completion of daily routines and spatial-temporal and social aspects of control. Participants either have time to participate in a period of informal consulting followed by formal consulting and planning for hospitalization, or they are thrust into the hospital systems moving quickly from informal consultation to intense formal consulting and hospitalization. As in the previous illustrations, those with unplanned hospital admissions experience abrupt losses of physical control that necessitate emergency hospitalization. Others plan their hospital admissions to address incre-

mental and cumulative losses of physical control that eventually compel them to have the losses professionally addressed. This participant refused to consider surgical reconstruction of the knee until it was the only option to regain control:

I had to build up the courage to do it. Well, I couldn't walk. I waited 20 years for this, because I tried arthroscopy twice. They said to me, 'You need a knee.' Six months ago, I went up the steps, it [knee] gave way. I couldn't walk. My daughter called him [orthopedist] and he said bring her right in. He said, 'She needs a knee. I'll give you a shot, be able to walk in 10 minutes.' But, I thought, he would say - we'll go in [for surgery] tomorrow, but a 4-month waiting list. So every month he gave me a shot to hold me over.

Consulting is an action or series of actions undertaken to begin to regain loss of control due to biological damage. It is done in order to both transfer and protect remaining control. Participants consult with and gain provisional controllers from both informal and formal sources. This action ultimately influences how participants work through Regaining Control.

Submitting. For the participants in this study, hospitalization was inevitable. The transition into the hospital requires them to submit or yield to the authority of hospital workers. Hospital workers are added to the group of provisional controllers already in place for these participants. In their role as formal provisional controllers, hospital workers control and direct hospital care to treat the illness or injury that damaged participants' biological capability. Hospital workers provide degrees of supplemental control in proportion to the severity of illness or injury and the resulting extent of biological damage. Submitting occurs when participants are unable to perform what is needed to maintain or

restore the biological damage that is necessary to regain control. As a result, participants must submit so that hospital workers may work to stabilize, restore, and monitor their biological capability. For example, a participant described submitting to workers in the operating room:

...the first time [UI]. I think it was right before I went on the OR table...I did a little [UI]. They had 11 people there. Just a frightful experience. [The people responded] Like I wasn't there. They were just going about their business. I didn't know any of them. Maybe one. They called two people in. Pass it off to two orderlies. I don't like to call them orderlies. Two nurse's aides? Just cleaned me up. Very gentle. Pain – a lot of pain. A lot. I was hoping that they gave me something... They brought a urine tube over after. Cleaned up. Don't remember the tube after that.

Participants relinquish degrees and aspects of control, consistent with the extent of biological damage and physical losses of control. This relinquishment can include minor aspects and amounts of control up to complete relinquishment of control. Complete relinquishment occurs when a participant is too sick or too tired to attempt Regaining Control or even care how hospital workers manage their bodies. This participant spoke about relinquishing all control:

When you are very, very sick, and at the beginning of my sickness... the world could've ended. It was okay with me, I did not feel good. I didn't care what you did to me, how you rolled me, who came to me.

Participants depend on hospital workers to facilitate biological recuperation and assist them to navigate the hospital space, time schedules, and social surroundings: *Once they*

[hospital workers] got me in a room. They got me moving around, going to rehab. Submitting completes the transfer of control. In order to regain control, participants rely on hospital workers to be formal provisional controllers supplementing the three aspects of loss of control to stimulate and facilitate biological recuperation.

The properties, consulting and submitting, are most notable during the transitional period from daily living to hospitalization. However, Transferring of Control and its properties may reoccur later in the process of Regaining Control in response to recurrent or new biological damage and losses of physical control. Illustrative of this was a participant who struggled with Transferring Control after surgery in response to a new loss of bladder control. Failing to initially recognize the loss of bladder control the participant passively consulted when hospital workers identified the issue. Subsequently, the participant actively consulted when she asked for a urology evaluation. Finally, she submitted to the authority of hospital workers:

[Field notes]: Hospital workers identified that a participant was experiencing overflow UI post-operatively and treated it by replacing an indwelling urinary catheter. [Quote]: I wanted a urologist. I don't know what is going on with the bladder...I am blocking that information out of my mind, because I do not want anything to be wrong with my bladder.

Participants hope and expect Transferring Control to be a temporary transition that will be short lived. Biological recuperation signals progression to the next phase. With recognition of biological recuperation and returning capability to physically control some of their actions, a participant's need to submit lessens. At this pivotal point partici-

pants begin working through properties of the second phase of Regaining Control, Exercising “Wobbly” Control.

2) Exercising “Wobbly” Control

Beginning with biological recuperation, Exercising “Wobbly” Control is a series of unsteady and iterative exertions of fluctuating control. A participant may recognize feelings of biological recuperation to physically control his body, but, at the same time, have feelings that this physical control waxes and wanes. Participants practice exercising returning physical, spatial-temporal, and social aspects of control by trial-and-error to gradually regain more and more control. Participants’ efforts to exercise “wobbly” control may, or may not, result in partial or full reclamation of control following each effort. During this second phase of regaining control, participants learn by interpreting and reflecting about how to successfully exercise “wobbly” control. They may recognize increased physical abilities and repeat actions consistent with orders and feedback from hospital workers. This participant, for example, relied on hospital workers to direct his control:

I was wobbly, but now I can stand on my own two feet. The sensitivity – by the head, and by the eyes, and how I feel – if I feel I can walk good, then I walk. If you feel you can’t – you can’t. So even if I could, I wait for them [hospital workers] to tell me I can walk by myself.

Participants iteratively enact five properties of exercising “Wobbly” Control: learning, following orders, directing provisional controllers, resisting, and concealing. These actions are dependent upon current conditions including the participant’s state of biological recuperation. Learning is interdependent and strongly linked with the other

four properties of exercising “Wobbly” Control. Participants cyclically learn and act, and learn and act, again. In doing so, they may enact any or all of the other four properties of Exercising “Wobbly” Control. Participants enact these properties both in isolation and in numerous interrelated combinations while working through the process of Regaining Control.

Learning. Participants filter current experiences in the hospital through their understandings of hospitals as they learn how their biological recuperation and provisional controllers influence their Exercising “Wobbly” Control. This Learning is accomplished by repeatedly observing, interacting, interpreting, and reflecting on actions taken (both their own and the actions of provisional controllers). Participants observe intrapersonal cues of biological recuperation. They observe and interact with provisional controllers for interpersonal cues that they are ready, and these provisional controllers will allow them, to regain control. Participants interpret and reflect upon combinations of intrapersonal and interpersonal cues in order to determine how to practice Exercising “Wobbly” Control and regain control.

Participants learn how biological recuperation signals a returning capability to physically control by observing intrapersonal cues:

I had the feeling like I had to go to the bathroom and I sat on the toilet and nothing wanted to come out... It [urine] just wouldn't come out, finally it did. I sat there [on toilet] until it did. For a few, it was like that. Then back to being normal.

Another participant shared observations of intrapersonal cues of biological recuperation that over a few days resulted in requiring less supplemental control from the nursing assistants:

Just a feeling comes to my head. Say I have to go to the bathroom, I'll walk it. A few days ago, I needed the assistant to put me in the wheelchair, the seat, and push me to the bathroom.

As participants attend to intrapersonal cues of biological recuperation they observe verbal and non-verbal interpersonal cues during interactions with provisional controllers. They interpret meaning from these cues and decide when and how to exercise “wobbly” control. One participant interpreted that his stroke greatly damaged his biological capability to regain control: *Damn stroke really did me in... I am a lefty [pause] spoon and spilling stuff. I've never had to use my right hand. I have much more control with my left hand, not now.* An interaction with his physical therapist (PT) supported this interpretation:

But even the therapist had eyes rolling the first time we talked and I said, 'Oh, by the way, I'm lefty.' He said, 'Oh, God, you're going to have to learn how to do things with your right hand, that's tough.'

With cues of biological recuperation, some participants are eager to exert and regain control. A participant began to feel better after her stroke and did not want to stay in the hospital. From interactions with doctors, she learned that it was too soon to be discharged from the hospital.

I was getting let out of the stroke unit. I wanted to go home. And like four doctors said, 'You can't go home. And if you want to do that then you have to sign yourself out. You don't want to do that, because you'll be back here.'

Participants also learn about Exercising “Wobbly” Control from the outcomes of their exertions. A successful outcome is the result of an exertion of control that is either consistent with the level of biological recuperation or a fortunate outcome of chance; both facilitate biological recuperation and result in regained control. Whereas, an unsuccessful outcome, such as falling, occurs when exertion of wobbly control is either not consistent with the level of biological recuperation or an unfortunate outcome of chance. This promotes a relapse to the earlier and more dependent phase of Transferring Control. Participants learn that outcomes fluctuate and are unpredictable. One participant had unpredictable episodes of UI (an unsuccessful and negative outcome) due to loss of physical control resulting in loss of spatial-temporal control because urine was *all over*:

And it [urine] poured all over the floor. I had to change all my clothes. It's an accident. It's all it is - is an accident. Incontinence [pause] but, yes an accident. You can't stop every accident from happening. You can try, but it's just going to be a situation that's going to happen...

He learned that when this loss of control required hospital workers to clean bed linen or the floor, they occasionally reprimanded him (loss of social control): *And some of them [nursing staff] will come in and start yelling at you, 'You were supposed to buzz me, you were supposed to buzz me you were not supposed to get out of bed.'* This participant understood he was taking chances, *Russian roulette*, when independently Exercising “Wob-

bly” Control that could, but did not, result in falling. Instead, amid the *accidents* there were times of control regained:

Going before I actually have to go. That’s the accident. Not falling. But it can happen: Slip and fall – it is dangerous ... I had to go and I couldn’t get to the bathroom, it [urine] went all over the floor. Other times he was able to make it in time... [I get] a feeling from the nurse that she’ll let it [the rule to call and wait for assistance] slide, I’ll pee in the bottle, leave the bottle, get back into bed. And no one will say the wiser – I won’t say anything, they [nurses] won’t say anything.

The previous illustrations demonstrate an uncertain probability of outcomes when independently Exercising “Wobbly” Control. Nevertheless, successful outcomes likely reinforce similar independent actions. Furthermore, participants with strong feelings of biological recuperation and desire to exercise control broadly interpret, or misinterpret, ambiguous behaviors of hospital workers. The result is an increased likelihood that they will misinterpret when and how to independently exert control as evidenced by a negative outcome. A participant misinterpreted what he heard during his therapy session about walking unassisted in his room. He had successfully exercised wobbly control a few times, which may have been by chance: *I got up to go [to the bathroom]. I had gone about 2 or 3 times before, by myself, before falling:*

What happened that day ... down here [PT gym] don’t remember who it was, there were so many people. I was under the impression that I heard that once I was strong enough to get up and walk by myself that is what I did. I heard them

say, 'Strong enough to get around the room by himself in the room.' [pause] I took it upon myself to hear what I wanted to hear about walking by myself.

Conversely, participants are more likely to correctly interpret explicit directions, orders, during interactions with hospital workers. This results in a greater chance that participants successfully exert control. A participant explained his choice to spend a good amount of time out of bed because nurses had specifically instructed, *'Don't lie in bed much. Sit in the chair all the time.'*

After Exercising “Wobbly” Control, participants reflect for varied periods of time. They interpret and re-interpret how to exert fluctuating control by reflecting on actual and potential outcomes. A participant quickly interpreted that other participants would be in their night clothing for a yoga session and chose not to change her clothes. Remaining in a hospital gown would be socially appropriate; the likelihood of risking a loss of social control was minimal:

An interview was interrupted by a transporter, who informed the participant about a 10 AM group therapy session. After which the participant reflected, 'She [transporter] did not say anything about getting dressed [pause].' The PI offered to take this concern to her nurse. In response, she shook her head and offered the following explanation, 'They [other participants] all go in their nighties, 'cause they are all elderly like me.'"

Or reflection over a longer period of time:

[Field notes]: After a few nights on the unit, a participant learned that about 1 AM all the bells would ring; [She] shared thoughts that during this time many participants needed assistance from the nursing staff. The choice of action that

exercised “wobbly” control and exemplifies regaining three aspects of control:
call for assistance before the rush of bells to avoid waiting a longer time for a nursing response.

Learning is an introspective property in which participants repeatedly observe, interact, interpret, and reflect upon intrapersonal and interpersonal cues, to determine how to enact the other four properties of Exercising “Wobbly” Control: following orders, directing provisional controllers, resisting or concealing.

Following orders. Participants follow orders by carrying out care routines prescribed and enacted by provisional controllers, particularly hospital workers. They follow orders to successfully exercise “wobbly” control by achieving milestones. Achievement of milestones provides evidence to their provisional controllers and themselves that biological recuperation and Regaining Control are occurring to the extent needed to go home. When participants follow orders they fulfill their social role responsibility of being a patient. Following orders include the prominent behaviors of calling or waiting for assistance from hospital workers.

With an understanding that hospitalization is to be a temporary means to regain control, participants follow orders. Participants perceive few to no other choices to regain control. One participant bluntly shared this perspective about needing the nursing staff to help regain spatial-temporal control after an episode of UI: *You have no choice, but to deal with the establishment, so [when] you wet the bed or you wet yourself, you have to own up to it and tell them, ‘Please change me’.* The participant came to this conclusion after previous instances during which he did not ‘tell them.’ In these instances members of the nursing staff reprimanded the participant and explicitly instructed him to tell the

nursing staff when he was wet with urine in order to avoid skin problems. By following orders participants exercise “wobbly” control in a way that they believe gets them closer to getting out of the hospital or as one participant said: *Each step in the gym is a step closer to the door out of here*. Following orders eases participants’ transition to Exercising “Wobbly” Control and provides participants with learning experiences that reinforce successful exertions of “wobbly” control because hospital workers direct how participants navigate their space and time until they are physically able to independently regain spatial-temporal control. A participant spoke about how hospital workers assisted patients in getting to the bathroom until patients reached the milestone of being given a walker. Using the walker regained some physical control and spatial-temporal control of self-toileting:

So if you weren’t able to use the walker, they [NAs] would bring the commode [a toilet-seated chair on wheels] to you then wheel you into the bathroom and you would go. Once they give you the walker you’re supposed to go to the bathroom yourself.

Participants learn that following orders achieves other biological recuperation milestones, goals met that demonstrate to provisional controllers and themselves that they are regaining physical control: *I did three hours of rehab every day ‘cause I wanted to go home*. Participants follow orders to achieve progressive but short-term milestone on their pathway to their long-term goal, regaining as much control as is possible in order to go home. These milestones include such events as: getting out of bed; walking the distance defined by hospital workers; transferring to less acute-care units; following definitive

discharge dates and locations. Each milestone requires participants to act in accordance with physical assistance or directives from hospital workers.

Following orders is a social responsibility of the patient role. Participants are responsible to themselves and their provisional controllers to facilitate their biological recuperation and return as much as possible to pre-hospital living. This requires participants to come to terms with their reliance on hospital workers and responsibilities of being a patient, such as *have[ing] to go to therapy*. This was illustrated in field notes that captured times when participants did not want to attend physical therapy sessions. During these instances, hospital workers informed participants of their responsibility to participate in the plan of care; a plan that includes therapy so that participants can practice Exercising “Wobbly” Control. Therefore, in response to the direct persuasions of hospital workers, participants who had sufficient biological recuperation followed orders to participate in therapy.

A common behavioral occurrence of following orders is abiding by the rule to call for or wait for assistance. Participants follow this rule to avoid reprimand by hospital workers, *they yell at you*; or unsuccessfully exerting control that may result in a worse consequence, such as a fall. Either of these consequences jeopardizes the control participants have regained at the present time. Participants risk loss of any or all aspects of control when not calling for or waiting for assistance from hospital workers.

You know – that I don’t get out of bed by myself and jump in this chair or walk around here. I have to go with that. I have to obey the orders, follow the orders, because that’s the hospital rules and one could get into trouble if they do not follow the rules.

When following orders participants successfully exercise “wobbly” control and facilitate how they regain physical control, spatial-temporal control, and social control.

Directing provisional controllers. When participants experience control regained from biological recuperation, learning, and following orders, they may exercise wobbly control in a social way directing their provisional controllers. In this way of exerting control, participants modify the behaviors of their provisional controllers to acquire more effective and empathetic supplemental control. More effective supplemental control facilitates Exercising “Wobbly” Control. Directing behaviors include: developing individual connections with hospital workers, asserting, negotiating, and training.

Some participants direct by developing and fostering individual connections among a variety of institutionally created relationships with hospital workers. They exhibit a variety of behaviors to express empathy and understanding, such as calling hospital workers by name or an endearing nickname, giving flattering remarks, joking, entertaining, and apologizing. This is done to receive reciprocal treatment:

You're not giving them command. Treat them as a patient carer. Yah, it's important. If you want them to care about you - to walk in your room with a smile and to be happy to help you, then you have to give them something back - appreciation, kind words, stuff like that. Then they come willingly to help you quicker.

A few participants directed hospital workers by asserting, or speaking up, for themselves.

I bitched, No, no, no loves, stop chatting, let's move it! [laughing] you have to say com'on girls stop your chit chatting about someone around the corner. I need to go to the bathroom. They thought I was quite funny.

She related her action of assertion to her individual character trait, *Well, I am outspoken*. However, in the context of her interview, she ascribed greater credit to biological recuperation and regained control: *As I got better, yeah I said, 'Girls, let's move it here.' [the nursing assistants helping this participant to the bathroom] **But** that's when you get better. That's why*. Furthermore, she used her understanding of hospital orders to direct the NAs: *You say you don't want me to go by myself and call for help. So let's go!"*

Other participants assert their needs to informal provisional controllers, but not with the same degree of empathy and understanding shown to formal provisional controllers. One participant described directing his wife to get the urinal quicker when a strong urinary urge would come: *And even sometimes during the day I would say, 'Babe', if she was on the phone or otherwise occupied I'd say, 'Babe, I need some help here. The feeling was really strong.'* Field notes captured the wife's perspective when she said: *[We had a] 'fight and he fired me - not quick enough'*. Participants direct by asserting, telling informal provisional controllers when to visit and how to provide assistance, supplemental control, when visiting.

- *[Field note]: A participant told spouse to not visit that day – to stay at home and rest. Assured spouse that all was OK, 'I am being good and doing what they tell me.'*
- *A participant had a friend provide help with going back and forth to the bathroom and changing brand-name diapers: 'As long as it is not a big mess. Then, little changes of pee-pee, not a big responsibility.'*

Other participants direct by negotiating. Over the course of a few days, a participant negotiated with nursing staff by repeatedly demonstrating to them that he would not

walk alone. He negotiated to have solitary time in the bathroom in order to exercise control of a *shy bladder*:

They [nurses and NAs] close the [bathroom] door now and I feel better. Because I told them, I got two or three days [before discharge] – you’ll be 5 min [if you close the bathroom door] or 5 hours [if you stand there watching me sit on the toilet] – then they listened.

At times participants have informal provisional controllers negotiate. *[Field notes]*:

- *Spouses briefly spoke about how they worked it out with the nurses to stay past visiting hours and provided hands-on assistance with care activities.*
- *A participant referenced having a cousin ‘represent’ her at the hospital’s interdisciplinary meeting to plan for discharge options.*

Participants may also direct by training provisional controllers about carrying out an established routine that may be unfamiliar to them. During a field visit, one participant explained and exhibited how she modified care delivered by her nursing assistant, who was working overtime after her usual night-shift:

She [NA] has never looked after me in the morning. Train the night-time carers. Their routine is different from morning carers. Simple things – brushing teeth for example – take me to the sink, near the sink. They [night carer] think I want to do it near the bed. I ask them to take me to the sink.

When Directing provisional controllers, participants need provisional controllers to be willing and able to respond. Among interactions with many formal provisional controllers, such as members of the nursing staff, re-directing is necessary. Participants experience different reactions from different members: *Well, each shift has different people*

reacting differently. Some will react fast, and some really wouldn't give a damn. When Exercising “Wobbly” Control during interactions with multiple hospital workers, participants concurrently and subsequently learn to behave differently with different hospital workers.

Resisting. Participants engage in resisting or defending against perceived threats to Regaining Control, especially to control regained. Participants resist in intrapersonal and interpersonal ways that are distinct from the initial denial, refusal, doubt, or inability to recognize a loss of physical control that initiates the process of Regaining Control as these ways specifically target protecting degrees and aspects of control that participants have regained.

Intrapersonal resisting occurs when participants defend their regained physical control by pushing themselves to exercise. This property of Exercising “Wobbly” Control occurs in later stages of their biological recuperation when participants have regained more of their physical control. Intrapersonal resisting strengthens physical control and lessens “wobbly” control. Participants struggle to regain physical control that, although still fluctuating, has become to some extent steady since the start of biological recuperation. A participant spoke about fighting to exert the physical control he had regained to protect it and, in turn, prevent losing control:

[Eye] was a little more blurry. Hard. I was wobbly walking. Now, thank God, Knock on wood [physically knocks table top], I'm ok. You see the trick of the trade is you gotta fight it. If you can't fight it - you got a losing battle.

Similarly, intrapersonal resisting behaviors were exhibited by other participants who pushed to work through difficult therapy sessions, getting to and from the bathroom, per-

forming personal hygiene care, such as face washing and teeth brushing, or other low risk activities, such as preparing their meal tray. After her indwelling urinary catheter was removed, this participant wanted to protect her bladder from being re-catheterized and resisted this relapse by physically pushing on it in order to empty it completely: *I even pressed my stomach to see if I would urinate some more.*

Participants enact interpersonal resisting when they defend against losing control by verbally or physically refusing to follow orders or offers of assistance from provisional controllers. If participants perceive that actions of hospital workers jeopardize any aspect of control regained, especially physical control, or may cause another loss of physical control or biological damage, these participants will resist following orders. Refusals may be blatant when they interpret that an order or action of a hospital worker is an imminent threat. Such was the case observed when a participant was being evaluated by a physician. *[Field note]: [The] participant resisted following the doctor's order of a sleeping pill. He reminded the doctor that he fell the night he had one.*

Participants may resist following orders if it means giving up regained spatial-temporal and social control. This was observed during a field visit. A participant obtained permission from hospital workers to schedule the study interview on the same date he made plans to have his family visit thus regaining, in this instance, some spatial-temporal and social aspects of control. However, at the scheduled interview time, a therapist came to conduct a therapy session. The PI observed the participant refuse to participate in therapy. Later during the recorded interview, the participant shared reflections about that interaction:

I expected to be comfortable today doing our interview. Prepare myself later – nice wash up – for my family coming...her [PT; nodded head towards doorway] coming in and saying we are going downstairs right away. I said, “Oh, no! No, we’re not [tone of anger]. I am not working today. I was told I have [today] off”.

Concealing. Participants conceal or mask signs and symptoms of aspects and degrees of loss of control. Concealing is a unique behavioral characteristic in that it is simultaneously enacted with other properties of Exercising “Wobbly” Control. It may be evident when participants follow orders, direct provisional controllers, and resist. Dependent upon the type and degree, physical loss of control may be more difficult to conceal in comparison to the spatial-temporal and social aspects.

Some participants conceal loss of bladder control to follow orders. Due to changes in the biological capability to control urination, the timing of urination becomes difficult to consistently interpret and physically control. Many participants spoke about changes to their biological signal to void: *that usual message you get in your brain that wakes you up from your sleep – isn’t there and when you gotta go – you gotta go*. Others said they *just leaked*. Some participants conceal lost urine by wearing diapers. Wearing a diaper contains urine lost, and, in turn, conceals this loss of physical and temporal control enabling the participant to be able to follow orders with a degree of spatial control knowing that urine loss is hidden: [Field note]: *able to travel to the therapy gym and get through therapy sessions ‘without wetting pants’*. Wearing a diaper promotes a feeling of, and exercise of, secure physical control:

Gives me security don't fall down – decreases risk of fall, because [name brand diapers] are quick – pull up one side then next and you don't have time to fall.

Our limbs are weak – cannot stand too long.

By wearing diapers, participants reduce work for hospital workers and themselves. In turn, they avoid being labeled a bother by hospital workers. These participants regain some social control because having a good reputation among hospital workers indirectly supports directing them. Taking 'away all that unnecessary work' was another form of 'giving back' to the nurses and nursing assistants as a part of developing connections and directing provisional controllers. Hospital workers highly favored this participant who [field note]: *never complains*:

They [nursing staff] like them [brand name diapers]. [Diapers are] easy to pull up, pull down, and change. [Diapers] Protect the environment, protect bed, take away all that unnecessary work of mopping up the bed. I am not guilty. I am not lazy all the time. Pee-pee in bed means the patient is lazy.

Other participants conceal by hiding negative feelings and 'being nice'. Different from how participants develop connections, this form of concealing masks expressions of negative feelings when following orders. This participant concealed his dislike for some hospital workers in order to be a good patient that would make his daughters proud (social control):

[I am] Not liking them [some hospital workers], but for the daughters' sake – so we don't get a little dirt on their white shoes. I want them [hospital workers] to say, 'He was very, very good – oh, he was a terrific patient. He did everything we

asked.' I want my daughters to beam. Temper. I don't curse, yell, scream. Um, conversation – good dialogue. I try. I talk with them, not above them.

Concealing negative feelings about hospital workers may occur when participants direct workers to assist them:

You gotta help me, I wet the bed. Please change me [pause]. Some are very nice about it, others are bitchy. You just have to grin and bear it. That's all. You deal with what you gotta deal with it. Not easily. You gotta grin and bear it, and to the nurse very nicely, some are nice about it and some are not. Some are sarcastic.

Some participants conceal when they are resisting. A participant concealed when resisting instructions to drink fluids as instructed by the hospital workers. She concealed this interpersonal resisting to following orders out of concern it would cause more UI:

Drink, drink, drink, - you're supposed to drink, but then if I do have to go the bathroom all the time so I don't drink that much and that's that. They [hospital workers] still tell me to drink a lot. They tell me everything's fine - fine. But when I wet the bed that's not fine I get embarrassed;

During Exercising “Wobbly” Control, participants practice exerting control that fluctuates with biological recuperation. Participants learn how conditions – biological recuperation, understandings of hospitals, and provisional controllers - influence following orders, directing provisional controllers, resisting, and learning. The priority to regain physical control supersedes feelings and desires for spatial-temporal and social aspects of control. In other words, at times participants may choose to temporarily give up, or not exercise spatial-temporal or social aspects of control in order to focus on regaining the physical control needed to be discharged home. Illustrative of this was a participant who

resisted having the therapy session on his previously negotiated day off from therapy.

This resisting was his initial response. In reply to his resistive behavior, the PT explained the necessity of therapy and the participant re-negotiated the schedule for the day with the PT. In doing so, he apologized to the PT, *I did say that [I was sorry] to the young lady.*

Later in the interview he explained how he followed orders to meet his needs to regain control: *Participation – [to] follow their example and what they [hospital workers] want me to do.* When biological recuperation plateaus and participants are consistently and successfully exerting control regained they begin to transition to the last phase, Adjusting to Degree of Control Regained.

3) Adjusting to Degree of Control Regained

When hospital workers decide a participant no longer requires hospitalization the transition out of the hospital begins and Adjusting to the Degree of Control Regained begins. This decision means a biological recuperation plateau has occurred and the participant no longer needs hospital care. This does not necessarily mean that a participant has full return of biological capability consistent with pre-hospitalization level. Rather, biological capability has resulted in a level of physical control regained such that participants must begin the transition home or to another healthcare facility. One participant who was nearing discharge from the hospital was thankful for feeling adjusted: *But now, thank God (knocking on table) I feel more and more adjusted.* In this instance, the participant was referring to independently managing toileting activities in the bathroom instead of having a nursing assistant wheel him to the toilet on the rolling commode. He acknowledged that he still was not at his pre-hospitalization level of independently walking: *[eye] slightly blur...lot of times when the nurse walks me and I am ready to make a*

turn, I think the wall is getting close to me. Participants adjust to the idea of reaching a biological recuperation plateau that may result in varied levels of physical, spatial-temporal, and social aspects of control regained. These levels may change over time and may be different from levels prior to hospitalization. The following participant was adjusting to the idea that urine control was unpredictable: *The individual cannot control it [urine loss] 100%. Fifty percent? Yes. Sixty percent? That's about as far as it can go.*

Participants get used to what can, and what cannot, be controlled. One participant spoke about how repetitive exertions facilitated acclimating: *I feel, doing it [using the bathroom] so many times, I am getting so used to it.* This participant knew what part of this physical action was under his control and what part was not. *I get up [from the toilet], flush it, wash my hands, and go back to the seat.* He knew that walking independently was not in his control. *[I must] wait for her [NA] to pick me up again.* This acclimating to the extent of control regained may occur with all or only some aspects and degrees control. During this phase, participants prepare for life after hospitalization.

Participants prepare for transition to a place where they will be able to safely engage in daily living. Ideally this place is home but sometimes it is a long-term care (LTC) facility. Participants prepare for this transition by reminiscing about how they dealt with other losses during their lifetimes. Drawing on past successes, they prepare accommodations to manage any residual aspects and degrees of loss of control after discharge from the hospital. This requires that participants reassign control from formal provisional controllers to informal provisional controllers or new formal provisional controllers. This final phase, Adjusting to Degree of Control Regained, has three properties: reminiscing, reassigning control, and leaving the institutionalized patient behind.

Reminiscing. As participants begin preparations to post-hospital living they engage in reminiscing or reviewing past losses experienced in life for the purpose of comparison to current aspects and degrees of loss of control. They review salient moments of their lives when they endured losses. Participants draw upon positive attributes as they review these losses or as one participant said: *I did not have much of a good life [pause] divorce, mother passed away;* and searched for innate strength: *I am determined to do [follow orders to get well]. I'm determined to be on my own.*

Participants recall how they managed previous losses in life. They review recent past events and remote past events and provide glimpses of lessons and skills from those past experiences help them continue to work toward Regaining Control. A participant attributed an ability to manage different people and situations because of previous work, recovering from alcoholism, as a member of Alcoholic Anonymous (AA):

I managed [sports] teams in AA. I learned to deal with individual personality.

Helped dealing with my type of work – because I was always dealing with new people. I try to catch myself in a daily routine, to try and do it right. Sorry is an easy word, 5-letter word. I can say that today.

Many participants reminisce about the events leading up to their current hospitalization. Some compare current degrees of loss of control to the losses that occurred during the onset of their most recent illness or injury. They recognize that those earlier losses were more life threatening or impeding than their present impairments. Participants use these initial events as a comparison marker that fosters their ability come to terms with and adjust to current degrees of physical control regained. A participant, interviewed after hospital discharge, recalled her time spent in the emergency room after the stroke:

I had [spouse] and my daughter on either side of me. That was the sickest I've ever been. And I only realize sitting here [in own living room] – that's how sick I was...I am okay now.

As some participants reminisce, they focus on how trusted individuals help them to make the best of life:

I gotta make the best. If it weren't for [daughter] I would have been gone a long time ago... Make the best. She comes tomorrow. I talk to her every day on the phone. She wants me to call her. So I call her. Feel good – good about it. Gotta make the best.

Often it is these trusted individuals that participants have relied upon as informal provisional controllers during the hospitalization period. At this point in the process of Regaining Control participants may look to these individuals to facilitate the management of their transition out of the hospital.

Reassigning control. In support of their transition and coming to terms with the fact that they have not yet fully regained control, participants reassign degrees and aspects of residual loss of control that still need to be supplemented. They actively or passively shift these current residual losses of control from one provisional controller to another. Often control is reassigned from formal provisional controllers to informal or new formal provisional controllers. The latter may include health care workers in nursing homes or ambulatory and homecare agencies. Biological recuperation strongly influences how participants reassign control. Participants who have a high degree of biological recuperation take an active role, while those with more severe residual losses of control reassign control in a more passive manner.

Active shifting of control occurs when participants, experiencing a greater degree of biological recuperation and regained control, are the primary controllers. This is most often the case for participants who have regained enough control to demonstrate to themselves, and to informal and formal provisional controllers, that they can safely manage at home. For this group of participants physical control is nearly at the level where the participant can independently perform pre-hospital daily routines. These participants actively reassign residual loss of control, mostly spatial-temporal and social aspects that have been managed by formal provisional controllers to either or both informal or new provisional controllers. They have these controllers supplement residual degrees and aspects of loss of physical control that participants need to perform daily routines and facilitate their transition out of the hospital. Illustrations of this are found in field notes noting how participants made arrangements with family members to manage tasks, such as filling the refrigerator with food or arranging transportation assistance to and from various appointments with doctors after hospital discharge: *[Field notes]: one participant was arranging dates for 'rides' from a family member for doctor 'check-ups.'*

Participants who have substantial residual losses of physical control and thus losses of spatial-temporal and social aspects of control, more passively shift control. Provisional controllers are the primary controllers who direct plans for the participant's transition out of the hospital. Participants may show degrees of shared controlling with these controllers. These participants passively reassign control to informal provisional controllers. Together, the participant and informal provisional controllers provide evidence to hospital workers that they will be able to safely manage living in the home setting. In one

such a situation, a participant stated he was *the last to know* about a discharge planning meeting:

[Quote]: What's her name [PT] called her [participant's girlfriend]. She called. When [girlfriend] came in one night for visiting, she said that she spoke to some woman – I have to be here Friday at 10 AM.

Field notes recorded that this participant did attend the Friday meeting as it was arranged and led by the participants' therapist and girlfriend who were preparing for his discharge back home. The girlfriend and PT were also planning a participant-termed '*furlough*' (visit home) in order for him to demonstrate his biological capability to safely manage his home environment with his girlfriend's assistance, a degree of supplemental control.

Some participants are unable to demonstrate adequate control regained. They do not have informal provisional controllers to safely provide supplement control for residual losses of control. These participants require alternative discharge situations, such as LTC facilities. They passively shift control to whichever provisional controller is the primary controller. This primary provisional controller then actively reassigns supplemental control to other formal or informal provisional controllers as needed. Field notes captured how a participant disabled from a stroke was discharged to a nursing home for additional therapy, while the spouse worked to get 'ducks in a row,' to make the home handicap-accessible to spatially accommodate the participant's residual loss of control, in hopes of eventually bringing the participant home.

Whether participants return home or are moved to LTC, they continue working and reworking through the process of Regaining Control dependent upon degrees and as-

pects of reassigned control and biological capabilities. For example, one participant who was planning to return home had not worn diapers while in the hospital:

I just did what I had to do. I had to use the urinal and made do and whatever.

They came and cleaned it up and went on. They [NAs] don't mind it [bed wet with urine], they do it [clean up urine] all day long.

Yet, this same participant was preparing to use diapers at home: *I ordered them [diapers], there - they are up there [pointed to top of closet]. A whole package came for me.*

He ordered the diapers because: *My wife told me to order them* (following orders). Field notes prior to the recorded interview captured how this participant worried about having an episode of UI at home on the carpet (spatial-temporal control).

Participants who shift control to LTC facilities face the possibility of needing permanent institutionalized living. While discussing pending discharge plans to go a nursing home, a participant stated, *I'm 85. How many can say they've lived to this age?* She suffered several episodes of respiratory distress, which resulted in being transferred to a specialty care unit, a prolonged hospital stay, and plans to be discharged to a nursing home. In a different way from the others, this participant shifted control to a 'higher power' or spiritual controller. This was evident when she spoke of her stroke and going to live in a nursing home as: *suffering is part of God's plan*. Those that go to a LTC facility address concern of loss of control in a new institutionalized setting and may not progress to the next, and final, property of Adjusting to Degree of Control Regained.

Leaving the institutionalized-patient behind. In addition to the participant's physical departure from the hospital, leaving the institutionalized-patient behind involves a period of forgetting unpleasant experiences of being a patient in the hospital. Partici-

pants do this in order to focus on returning to daily living. Forgetting unpleasant experiences has an undefined ending, which may occur well-after discharge or may never completely occur. Loss of control elicits feelings of concern, as expressed by the following words used by participants': *apprehensive, embarrassment, anger, horrible, and frustration*. These feelings are strong and may linger after the hospitalization for primary illness or injury and any subsequent biological damage, such as new-onset UI, a fall, or a relapse of the primary ailment that caused the need for hospitalization. About two weeks after hospital discharge one participant, who suffered a debilitating stroke, recalled: *I was frightened; between being in the hospital, the ambulance, the MRI, all of that – scary experience.*

Participants demonstrate deliberate forgetting of the events during hospitalization. After discharge from the hospital there is still a purposeful and wishful forgetting.

[Field notes] Two months after being home, a participant reported the indwelling urinary catheter was removed 'two weeks after discharge.' At that time, the bladder was 'almost back to normal'. The 'hospitalization, new-onset overflow UI, foley,' were a 'nightmare' she 'wanted to forget'; bladder control was regained: 'plumbing works just fine.'

Deliberate forgetting is different from illness-induced forgetting that occurs when participants are at their sickest or most disconcerting moments during hospitalization. During these moments they simply cannot recall some events even when consciously making an effort. This was evident when a participant, who was detail-oriented, tried but failed to recall what happened during the hours after surgery: *...what happened from when I came up from surgery [pause] I guess I don't even remember what happened.*

Participants approach the end of the process of Regaining Control when they are home and beginning to participate in the routines of their daily living. They accept and adjust to the degree of control regained, and engage in new routines of daily living or re-engage in the old routines as their biological recuperation permits. This successfully resolves their concerns of loss of control and about getting out of the hospital and going home. One participant interviewed after discharge hospital was happy to be home, but had not completely regained physical control consistent with pre-hospitalization level. This participant, who had been home for about two weeks, wanted to be better, but felt adjusted: *I would like to be better, but I've been out and about...I am OK now, I have things to do.* Although she still had residual losses of physical control, she had regained satisfactory degrees of spatial-temporal control and social control:

[Field note]: interview in home with spouse present: [Quote]: Now when my kids come by, and ask me how am I feeling? How am I doing? I tell them I'm okay. I just tell them I'm moving along...They say my voice is better [present time]. But I don't know because I don't have my teeth in and I have to go to the dentist. But I feel good. ..this bathroom here [points to home's] is closer than any bathroom there [hospital]. I don't have any problems here... I'm very glad to be home. I got things to do ... a lot of kids, a wedding this year, a wedding next year.

Regaining Control is a complex process that explains how participants continually work to address their concerns about loss of control. For the sake of clarity, the sections detailing the three phases - Transferring Control, Exercising “Wobbly” Control, and Adjusting to Degree of Control Regained – and their properties were written in a linear fashion. However, these phases, are not linear and do not follow a steadily increasing pattern

or forward momentum towards Regaining Control. During the process of Regaining Control participants may lose and regain control over some aspects, while retaining or losing others. For example, participants might, at times, regain some aspects of control only to experience a biological relapse that causes them to rework the phases and properties of Regaining Control again and again. In addition to the process of Regaining Control three conditions emerged during the study as modifiers helping to further explain how participants work through the process of Regaining Control.

Conditions

In the hospital setting, three conditions - biological recuperation, understandings of hospitals, and provisional controllers - influence how participants work through the process of Regaining Control. Biological recuperation, an involuntary and not entirely predictable return of biological capability, is needed for participants to progress and regain control. Participants experience biological recuperation at various speeds and to varying degrees. Participants and their trusted individuals, who become informal provisional controllers, enter into the hospital with varying understandings of hospitals. A lack of experience or a negative experience affects a participant's current hospitalization as does greater amount of experience, a positive experience or insider knowledge of hospitals. Informal provisional controllers contribute degrees of understandings of hospitals as they work together with formal provisional controllers, albeit possibly to a lesser degree during hospitalization, to supplement degrees and aspects of loss of control for participants.

How these three conditions interact and evolve, or not, influence the progress and degree to which participants regain control. Three examples demonstrate different ways

that these conditions influence a participant's return to home after hospitalization. The first example, when the level of biological recuperation is high, understandings of hospitals are extensive, and informal provisional controllers are able to provide adequate control to supplement for residual degrees and aspects of loss of control then there is a strong likelihood that participants will return home. Such was the case for one participant who had regained a good deal of physical control after a stroke and had a spouse, an employee of the hospital, provide supplemental control. The spouse took vacation time to stay home and facilitate the participant's transition back home: *[Field note] 'two weeks of vacation time' in order to be 'around to help' at home.*

The second example, illustrates moderate levels of biological recuperation and understandings of hospital from past personal hospitalizations, and an informal provisional controller able to provide supplemental control, but not in the home of the participant. This participant planned to be discharged to a sub-acute rehabilitation facility and then to his daughter's home. He was hesitant to call for assistance from the nurses because they were not in the room as nurses were during his last hospitalizations. He worried about bothering them because they were always so busy. He reported feelings of biological recuperation: *in the beginning [of hospitalization] I'd wet the bed, but I have the feeling [pause] I am fine now.* In addition, field notes captured that his unsteady walking became steady enough for him to perform the majority of self-care activities. At the time of the recorded interview, his daughter was preparing to accommodate him in her home.

The third example, when the level of biological recuperation is low, understandings of hospital are minimal, and informal provisional controllers are not able to provide control to supplement for residual degrees and aspects of loss of control, then there is a

strong likelihood that participants will require institutional care in a LTC facility. Another participant did not report feelings of biological recuperation after 27 days in the hospital, *I don't stand too well*, and field notes captured her limited biological capability to perform self-care activities. She and her family *let staff do their own thing*. She did not have informal provisional controllers capable enough to provide the supplemental control needed to safely manage her at home. At the time of the recorded interview she was adjusting to the plan to be discharged to a nursing home.

Biological recuperation. Participants referenced uncontrollable and somewhat unpredictable biological factors that affect their capability to regain control. Ongoing biological recuperation results in a desire for more control, diminishes reliance on provisional controllers, and facilitates transition through the second and third phases, Exercising “Wobbly” Control and Adjusting to Degree of Control Regained. Biological recuperation is the primary facilitator for how participants regain physical control. It commences as soon as effective medical treatment and therapies begin and continues after hospitalization for a period of time. The occurrence and severity of a relapse or new loss of control may have a minor or major effect on Regaining Control. For some participants, biological recuperation does not reach the level needed for them to regain enough control to safely return home.

Biological recuperation requires variable amounts of time. One participant spoke about new-onset UI that was worse when *incapacitated ... as time moves on - you are able to move more, feel more, that you have to go [urinate]*. Field notes captured how a participant, interviewed after discharge, recalled not being able to sign her name in the hospital. Over a course of a few weeks at home, she was able to sign the consent for this

study: *I couldn't even write my name ...now I can.* Writing was not a task practiced. It was the first time the participant attempted to write since returning home and signaled further biological recuperation after returning home. Other field notes captured how a different participant interviewed after hospitalization spoke about the continued ‘hassle’ of still needing a walker, a hospital bed in the living room, and thrice weekly PT sessions. This suggests that return of biological capability needed to regain physical control is ongoing and beyond the control of both participants and their provisional controllers.

Relapses of the original illness or injury, or new illness or injury, hinder biological recuperation and how participants regain control. This hindrance may be minor or major. Loss of bladder control resulted in a range of minor to major hindrances. When UI is concealable or does not persist it is a minor hindrance. One participant, who wore diapers, was not very concerned about urine leakage: *As long as they [hospital workers get me to the bathroom. As long as I feel secure [and am] not peeing for everyone to see.* Another participant viewed a single episode – just *the once* - of urine leakage as a minor hindrance: *Oh, that was just a matter of not being fast enough to get there [bathroom].* This participant had fallen when returning to his bed, which may be considered a relapse.

Other times when participants are unable to conceal UI lost urine, they experience difficulty following orders, a property of Exercising “Wobbly” Control. The effect of this relapse is a delay in how control is regained. A participant was unable to follow orders due to an episode of UI that resulted in an unpredictable *before I knew it I was wet* sensation. Inability to control urination delayed her attending and participating in scheduled therapy (spatial-temporal control), which hindered her exercising “wobbly” physical control. Field notes also captured a participant’s observation, confirmed by PTs, that if a ‘pa-

tient wet themselves in the gym, they are sent back to the unit.’ If the UI cannot be concealed, and it becomes a regular occurrence, or is linked to a fall, this loss of bladder control may greatly influence Regaining Control.

A few participants suffered major relapses that prevented biological recuperation from reaching a level needed to go home. These participants required extended institutionalized care in LTC facilities. They did not regain control, such as a participant whose biological capability did not return to facilitate regaining physical control despite going to therapy: *[This is] Something [standing and urinating] I cannot control so I cannot help me.* Another participant, interviewed after discharge in a nursing home, spoke about his dominant side that no longer worked: *So, lefty everything is fine. But it [left arm] doesn't work at all that's the problem.* These participants did not experience the needed degree of biological recuperation to process through Regaining Control. They were unable to leave the institutionalized-patient behind and go home.

Participants who do not recuperate to the extent needed to go home re-work phases and properties of Regaining Control. For example, they continue to submit and follow orders, because they are dependent upon formal provisional controllers. Participants who did not recuperate enough to be able to self-manage their bodies relied on formal provisional controllers to perform basic hygiene and activities of daily living. Field notes captured how a participant who was not meeting biological recuperation milestones submitted to have [Field note]: *diaper checked and changed by two nursing assistants.* This participant did not exhibit directing or resisting behaviors. Participants who are discharged to nursing homes continue working through Adjusting to the Degree of Control

Regained, but as long as they remain an institutionalized person they cannot process through the property of leaving the institutionalized-patient behind.

Understandings of hospitals. Beginning with the initial onset of illness or injury, experiences before, during, and after this current hospitalization are filtered through a participant's understandings of hospitals. These understandings, or perspectives, are shaped from past hospitalizations or experiences with hospitals. Prior hospitalizations influence what participants understand to expect during this current hospitalization. A past hospitalization influenced what one participant perceived as controllable during the current hospitalization. Since she could not control the response time of the nursing staff, she wore diapers to conceal urine lost [*Field note*]: *participant knew from last time to wear diapers because nurses don't always get to you on time.* Generally, participants lack or have negative understandings of hospitals. Participants understand that hospitals are necessary to treat illness or injury and must be regimented to service many patients and decrease liability. Some participants have greater understandings about hospitals accrued from previous hospitalizations or insider knowledge.

Negative understandings of hospitals may delay the first phase, Transferring Control. Some participants view hospitalization ambiguously. They perceive hospitalization as both a hazard to be avoided and a necessary means to regain control. A participant complained about a prior hospitalization that almost killed him. *No one [hospital staff] listens. Years ago, [there was a] rush to do [an] MRI then finally the tech said, I'll kill you if I put you in. Metal stent.* Yet, with respect to the current hospitalization, he blamed himself for delaying his care and not going to the hospital right away with the first sign of his stroke: *If I wasn't so thick-headed, I'd probably still have my speech.*

Participants understand that hospitals are regimented. Regardless of physical control regained certain spatial-temporal and social aspects of control are not ever in control of patients when in the hospital. During field visits and interviews participants referenced crowded emergency rooms (ERs) and rules and regulations that govern regimented routines, such as physician rounds, therapy sessions, and food tray delivery. One participant explained not liking, but understanding why his room was close to the nursing station:

Keep me away from nurses station, but then again – watching you instead of pushing button. It has its advantages and disadvantages.

Influenced by this understanding that hospitals are regimented, participants continue submitting to certain aspects of hospital care. They submit even if the rules do not make sense to them and they have recuperated enough to follow orders, direct, or resist. These participants do not attempt to control space-time and social surroundings that are controlled by the rules and regulations governing the hospital. Moreover, submitting to hospital workers, who monitor biological recuperation, is necessary in order to receive necessary hospital treatment for their biological damage. The following illustrates how a participant momentarily resisted, but then submitted to the transporter, who took him for a needed diagnostic test:

[Field notes]: An interview concluded as the meal tray arrived. During the time that the participant began to prepare to eat, a transporter arrived with a wheelchair. The participant stated to the transporter, 'NOW? Dinner will get cold.' The transporter [a young lady who fidgeted as she implored], 'Yes now, I am doing what I am told to do. They can heat your dinner when you get back.' In reply, the participant covered his meal, 'Let's go.'

Participants understand that rules and regulations must protect many patients and hospital liability, while, at times, limit the degree to which participants may individualize. Exercising “Wobbly” Control: *Nurses have a whole mess of people and can’t just drop everything and run to [me]*. The participant understood why nurses were closely monitoring him because he had fallen once during the night and their fear of a lawsuit: *I can understand that [suing], but it [fall] wasn’t their fault – it was mine*. A participant did not follow orders, calling for assistance when getting out of bed and going to the bathroom, (resisting) based upon his understanding of hospitals. This participant knew he was not supposed to independently go to the bathroom, but chose to do it anyway. He understood that the rule to call for assistance was not derived from an evaluation of individual needs - he never felt so weak that could not make it to the bathroom on own. He understood that the rule was to protect the hospital’s position, which was to avoid a lawsuit.

[Field notes]: *Not supposed to go to bathroom on own, but does it. Hospital’s position – lawsuit. Never felt that weak – being restricted was hospital’s position, not his. [Strength] Different than at home, but not to point where ‘I need someone to get from point A to B.’*

Participants may have a good deal of understandings of hospitals. One participant, who had worked in health care, had two recent hospitalizations that included staying on the same unit. She knew from her insider knowledge and past experiences about the importance of participating in therapy [Field notes]: *in the past she’s been told to bear with pain*. This influenced how she pushed herself to exercise despite feeling pain (intrapersonal resisting). Field notes also captured how her nurse knew her well from her past hospitalizations. The nurse offered a cup of tea when preparing pain medications; to

which the participant smiled and thanked her. This instance provided data to support a development of an individual connection.

Other participants have informal provisional controllers with insider knowledge who influence how participants regain control. A participant, who suffered a stroke that substantially impaired his biological capability, learned from his wife, a nurse, who controlled his voiding schedule and fluid intake by *[Field note]: offering urinal every three hours; brought and labeled a graduated drinking bottle to monitor fluid intake*. With this supplemental control from his wife this participant was able to regain periods of full bladder control. Another spouse worked in the hospital. Having this insider understanding helped to develop individual connections for the participant thus facilitating Exercising “Wobbly” Control: *Well, now, they [hospital workers] were extra, extra good to me... because [spouse] works there so it was like family. They let my [spouse] stay. They let my daughter stay.*

Provisional controllers. Provisional controllers are comprised of two main groups. Formal provisional controllers can be any type of paid healthcare worker including, but not limited to, emergency responders, doctors, various therapists, nurses, and nursing assistants. The second group, informal provisional controllers, consists of informal caregivers made up of trusted family members or friends. Each in this group influences how participants process through Regaining Control by providing degrees of supplemental control. Their actions modify the physical, spatial-temporal, and social aspects of loss of control for the participant. There is a dynamic relationship among participants and these two groups of controllers. How this relationship changes is dependent upon the participants’ biological damage and recuperation. During time periods of acute biological

damage, participants experience loss of control past a point that informal provisional controllers are able to provide sufficient supplemental control. It is during these times that participants and their informal provisional controllers are most dependent upon the skills and expertise of formal provisional controllers to take control and direct care:

It seems every time I threw up I wet myself. The worst part of it was in emergency.

They always kept changing me. My youngest daughter was with me and pop [gestured to husband] they took care of me. And if they couldn't take care of me - the people in the hospital would take care of me.

Whereas, as the participants regain degrees and aspects of control the prominence of supplemental control provided by formal provisional controllers shifts to informal provisional controllers. Instances of notable variation occur when informal provisional controllers are absent or incapable of providing supplemental control proportional to the nature of the participant's loss of control. Participants hope supplemental control is temporary:

Instead of being here [hospital] – I should be home. So you gotta hope and pray...

Wonderful hospital, food, service, the nurses. I hope this stroke don't come again.

Nothing like home sweet home ... you gotta take care of yourself and hope everything is alright.

Formal provisional controllers. Participants are affected by how hospital workers implement the rules and regulations of the hospital. These rules and regulations of the hospital are driven by health care industry regulations and accreditation standards that influence hospital policies: *[Field note]: hospital had prominent signage of accreditation from The Joint Commission [a non-profit credentialing agency].* The manner in which

hospital workers interpret and enact, or not enact, hospital policies influences how participants regain control. For example, the fall prevention policy [*Field note*]: *posted on bulletin boards located on both the first floor rehabilitation gym and the inpatient unit at the hospital of study*, requires medical and nursing staff to implement a set of procedures to prevent falls. As a result, hospital workers restrict patient autonomy in order to promote patient safety. Their use of mattress and chair alarms, electronic alert devices with pull strings or pressure devices that aurally alert nursing staff if a patient gets out of a bed or chair unattended, restricted participant movement. These alarms sound when participants reposition themselves in the chair or bed. Some participants resisted implementation of these safety alarms because they disrupted sleep.

Institutionalized bladder protocols direct nurses to identify cause of urinary incontinence and reduce environmental barriers. This was rarely noted in verbal communication among nurses and not noted in nursing documentation. In addition, during field visits there were times that needed objects - specifically the urinal or call bell - were not within reach of participants and other patients. This discrepancy between policy and actual implementation hindered Exercising “Wobbly” Control. Participants did not consistently have these needed devices available to regain control of their bladder. One participant spoke about having bladder control if he had his urinal within reach: [*Field note*]: *independent if have the bottle [urinal]*, but this was not always the case. Another participant spoke about environmental barriers that hindered her safe self-toileting. Her efforts of *directing provisional controllers*, in this case nursing staff, were not effective. Therefore, she held her urge to urinate (resisting) for as long as possible.

The nurses that would bring the other patients into the bathroom - they wouldn't lock the commode. They wouldn't lock the commode. So now I have to go to the bathroom and I went sliding. So after that, I had to check that all four wheels were locked. And I said to the nurse, 'When you bring the commode back to the bathroom - could you lock it?' And they never did. I would have to go with my foot [made motions] to make sure it was in a locked position then I would go like this [gestured that she would shake the commode]. So to me - to go to the bathroom was a hassle... When I was in a private room it was great. It was my BR - I knew it was locked. When I went in the room with the three [patients] - the thing went sliding. To me, I [would] rather hold it in then have to go locking...and it was not very clean that hospital ... [laughed in a disappointed tone]

The attitudes and behaviors of formal provisional controllers influence participants work towards Regaining Control. Therapists did not regularly include toileting routines during therapy sessions. From these interpersonal cues participants learned that the best time to use the toilet was before or after therapy sessions, not during:

Went [to the bathroom] upstairs [on unit], because once you were in rehab - I don't think they [therapy staff] wanted to be bothered with [it] ...I think maybe once I had to go to the bathroom. Normally, I would go to the bathroom before I go to rehab and then when come back - go again

When participants assert themselves (directing provisional controllers), formal provisional controllers may provide degrees of supplemental control consistent with the degree of biological recuperation and level of physical control regained. One participant who had undergone planned joint surgery recalled asking the therapists if she could use the

bathroom: *They [therapists] took me in. I did what I had to do. They were right outside.*

A different participant who had disabling left-sided weakness from his stroke recalled:

We [therapist and participant] went together and he showed me everything. It was the first time I had gone there [bathroom] during a training exercise. He said, 'Oh yeah tell me right away you should not have any pressure on you'

Informal provisional controllers. During the process of Regaining Control, participants in some sense chose trusted individuals who become informal provisional controllers. These controllers provide supplemental control ranging from offers of sentimental get-well wishes and bringing needed personal belongings to augmenting hospital care. Participants are comforted when these controllers visit and bring needed belongings. The following illustrates how a seemingly simple act of a daughter bringing glasses during scheduled visiting time in the recovery room enabled a participant to see (regained physical control) and feel better: *It was good when I saw my daughter because she did give me my glasses. I cannot see without them. Just seeing my daughters there made me feel better.*

Other informal provisional providers provide cheerleading and incentives for Regaining Control. One participant lived in two states. Her room was adorned with cards, flowers, and balloons from friends in her retirement state: *Everyone is praying for me and hoping that all goes well and [asking] 'How soon are you coming back?' [pause] We'll see. I'm going back as **soon** as I can.* Another participant's son tried to motivate her to get well enough to attend a long-distance family social function, but this was ineffective:

That's all I hear every time he talks to me. 'Mom, waiting for you.' Right now I can't. So what is the sense of me going? I can't walk. I can't drink, and another

thing, I get tired very easily so what's the sense of me going? He'll have to realize that I'm too old to go. He says, 'Mom we'll have a lot of fun'. I know you will - I would go too if I could, but I feel like I can't go; and that's an awful feeling.

Informal provisional controllers augment the supplemental control provided by hospital workers and facilitate participants' Exercising "Wobbly" Control. Those with insider knowledge help individualize Following orders for participants. They may provide simple but highly effective supplemental control for one patient as opposed to formal provisional controllers who provide supplemental control for many patients. This individualization of supplemental control means that participants are more likely to have assistance when they want or need it. These actions by informal provisional controllers allow the participant to more effectively exercise physical and special-temporal aspects of "wobbly" control and not call for, wait for, or bother provisional controllers. The informal provisional controller lessens their workload allowing the participant to regain some social control. Additionally, this augmentation of care may help the participant be labeled as a good patient by hospital workers and in developing individual connections. Field notes captured how hospital workers referred to one participant and spouse as *sweet* and *a pleasure*:

A lot of times, when the ladies [nurses] were busy, [spouse] was in the room and walked me to the bathroom. I would tell him, 'Just get me there. I can take care of me.' I wouldn't have known what to do without him.

Summary

Participants' main concern is about loss of control: physical, spatial-temporal, and social aspects. They want to get well, get out of the hospital, and go home. To resolve

these concerns, participants work at Regaining Control. This complex three-phase intrapersonal and interpersonal process is how participants constantly work to regain control. The first phase, Transferring Control, begins before hospitalization when participants act on their loss of control triggered by illness or injury. They consult informal and formal sources and then submit to being cared for by hospital workers. With biological recuperation participants begin the iterative process of Exercising “Wobbly” Control. With ongoing biological recuperation, participants learn how to successfully exert fluctuating control. Initially, they accomplish this by following the orders from hospital workers. Progression through this phase includes enactment of directing provisional controllers, resisting, and concealing. When participants have reached a biological recuperation plateau participants must prepare their transition out of the hospital to home or a LTC facility and begin Adjusting to Degree of Control Regained. During this phase participants acclimate to degree of control regained by reminiscing about past endurances of losses in life, reassigning control of residual degrees and aspects of loss of control to informal and formal caregivers, and leaving the institutionalized-patient behind. Regaining Control is heavily dependent upon biological recuperation, an individual condition. Other influencing conditions are participants’ understandings of hospitals and provisional controllers. Participants come to the end of the process of Regaining Control when they accept and adjust to the degree of control regained and are participating in the routines of their daily living.

Chapter Five

Discussion of Findings

Understanding loss of control from the patient perspective and how they work to regain control during hospitalization is essential given that fact that American health care is undergoing reformation to deliver patient-centered care. Over a decade ago the Institute of Medicine (IOM, 2001) outlined six core needs, one of which is patient centeredness, with 10 rules compelling redesign of the healthcare system. The third rule declared:

The patient is the source of control. Patients should be given the necessary information and opportunity to exercise the degree of control they choose over health care decisions that affect them. The health system should be able to accommodate differences in patient preferences and encourage shared decision-making. (p. 61)

... the care system will take control only if and when [patient] freely give[s] it (p. 63).

For hospital systems, the naturalistic findings of *Regaining Control* describe and explain a much richer and nuanced view of how participants embodied control after suffering its loss. These findings elucidate loss of control that support, modify, and expand several concepts of control. In addition, the influence of hospitalization on how participants worked to regain control is illuminated. The theory of *Regaining Control* provides initial underpinnings to understand the relationship of control and patient-centered care. Comparison of the current findings to the extant literature suggests that effective hospital care is not about taking control away from patients or giving complete control to patients, but, instead, it is about sharing control. Although the results of this study provide a unique view of control specifically from the perspective of hospitalized older adults with new-

onset UI, the resulting theoretical framework is likely consistent with the broader population of hospitalized adults. This suggests a pathway of how control may be shared among patients and those who take on the role of provisional controllers.

Control Literature

The findings of *Regaining Control* describe and explain the nature of control during a period of crisis, hospitalization. Two comprehensive reviews of control identified over 100 varying uses of the word control (Jacelon, 2007; Skinner, 1996). The majority of these terms focused on perceptions of control and not the action-oriented control that was found to be the focus of participants in this current study. Many articles focused on defining perceived control, globally or specifically to an aspect of life, but no consensus definition was identified (Jacelon, 2007). This is notable since there is considerable support for the idea that perceived control has a strong influence on one's actions (Jacelon, 2007; Skinner, 1996). If this is so, one must first have an understanding of how control is experienced, a product of external conditions, subjective interpretations, and their actions, in order to optimize a group's function (Skinner, 1996).

Within the behavioral patterns found in the theory of *Regaining Control* there were instances of perceived control. Participants learned from their interactions, observations, interpretations, and reflections, all of which influenced how participants exercised "wobbly" control. These perceptions were influenced by the participants' main concern over loss of control, and also influenced their actions towards regaining identified, action-oriented aspects of control. The theory of *Regaining Control* provides information necessary to begin an optimization of this process by offering an understanding of how hospitalized older adults with new-onset UI respond to an action-oriented loss of control that is

not found in the literature. Identification of the main concern, *loss of control* and discovery of how participants responded, the theory of *Regaining Control* supports, modifies, and expands four related concepts of control: external control (Rotter, 1966) relinquishment of control (Miller, 1980), proxy control (Bandura 1997), and participatory control (Reid, 1984). Each of these concepts addresses the premise that, during times of crisis, individuals need powerful or more competent others to control what they, themselves, are unable to control.

Loss of control

The three aspects of loss of control identified in this study - physical, spatial-temporal, and social - seem to be missing or unobserved by other researchers in the literature. Others reference but did not define loss of control (Bandura, 1997; Boltz et al., 2010; Dickerson, 2002; Heckhausen & Shultz, 1995; Hupcey, 2000; Johnson & Morse, 1990; Miller et al., 1989; Morken et al., 2009; Reid, 1984; Sjudahl et al., 2008; Skinner, 1996; Truant & Bottorff, 1999). In this literature, unexplored anecdotal references to loss of control were mentioned, but the trigger for and pattern of loss of control were not detailed. Although undeveloped these references indicate that an action-oriented loss of control is of concern to patients. Extant literature along with current findings, provide a broad and practical understanding of how action-oriented control is affected when illness or injury requires hospitalization.

The health science literature, with a focus on control, contains many anecdotal indications to loss of control using terms, such as “loss of control,” “lack of control,” “limited control,” “losing control,” “failure,” “reduced feelings of control,” “loss of personal control,” and “not being in control” (Bandura, 1997; Boltz et al., 2010; Heckhausen &

Shultz, 1995; Hupcey, 2000; Larsen, Larsen, & Burkelund, 2013; Miller et al., 1989; Reid, 1984; Sjodahl et al., 2008; Skinner, 1996; Taylor, 1979; Truant & Bottorff, 1999). Only the work of Taylor (1979) seems to closely relate to the loss of control identified in this study; that is patients experienced a forfeit of control to hospital staff during hospitalizations. Taylor described loss of control as depersonalization, a situation-specific and well matched perspective of the spatial-temporal and social aspects of control identified in the current study. Others have also suggested that the institutionalized setting depersonalizes clinical encounters (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Larsen et al., 2013). In contrast to current findings about loss of control, Taylor only focused on these two aspects and did not account for the biological trigger, injury or illness that resulted in loss of physical control, a third aspect of loss of control identified in this current study. Instead, Taylor essentially attributed patients' loss of control to the unpleasantness of the hospital environment. Current findings about a biological trigger align well as an antecedent to Taylor's (1979) anecdotal observations that hospitalization causes a loss of freedom.

Although studies in other substantive areas also allude to instances of physical, spatial-temporal, and social aspects of control, they do not directly discuss it as a major research finding (Dickerson, 2002; Hupcey, 2000; Johnson & Morse, 1990; Morken et al., 2009; Sjodahl et al., 2008). These anecdotal occurrences include instances in studies of patients recovering after a heart attack (Johnson & Morse, 1990), lower extremity amputation (Sjodahl et al., 2008), and internally implanted cardiac defibrillators (Dickerson, 2002; Morken et al., 2009). Amputees had 'limited control' overall to be able to understand the reason or prepare for losing a limb (Sjodahl et al., 2008); while individuals with

internal defibrillators sensed a loss of control of their former lives (Dickerson, 2002). Patients in each of these studies struggled to address new biological limitations caused by illness or injuries. These researchers did not define action-oriented boundaries of loss of control. However, they did focus on psychological aspects of control that targeted areas similar to aspects identified in the theory of *Regaining Control*: predictability, self-determination, independence, and changed relationships with partners (Johnson & Morse, 1990; Morken et al., 2009). Independence and changed relationships are most similar to current findings that addressed biological capability and social control. Hupcey (2000) used Grounded Theory methodology to identify the psychosocial needs of patients in an intensive care unit. Even though instances of all three aspects of loss of control were reported, they were not analyzed as meaningful aspects of loss of control. Hupcey noted that patients exhibited intense feelings of loss of control including an inability to self care (physical control), inability to control visiting hours (temporal and social control), and confinement to bed (spatial control), but these findings were not grouped in a way that related to behavioral patterns of regaining control. Current findings coupled with findings from these studies provide support for the three aspects of loss of control during hospitalization, which, until now, had not been categorized. Categorizing these three aspects from the patient perspective defined an action-oriented control, a catalyst for the identified behavioral patterns of participants as they worked at *Regaining Control*.

Four Concepts of External Control and Provisional Controllers

Although the substantive area of this study was hospitalized older adults with new-onset UI, another group emerged as relevant to how the participants responded to loss of control. This emergent group was labeled provisional controllers, those who pro-

vide supplemental control to participants. Loss of control logically increases one's dependence on a source of external control. In the extant literature, locus of control of reinforcement (Rotter, 1966), relinquishment of control (Miller, 1980), proxy control (Bandura, 1997), and participatory control (Reid, 1984) similarly addressed how individuals relinquish control to others they perceive to be more powerful or competent than themselves. These researchers focused more on an individual relinquishing control rather than individuals entrusted with the relinquished control. The theory of *Regaining Control* provides description and explanation of naturally occurring behavioral patterns that suggest the need to examine overlap among these four concepts of control and the two groups of individuals involved. The nuanced behaviors identified during the process of *Regaining Control* are similar to that of participatory control. In both *Regaining Control* and participatory control, the interactive nature of the passing and relinquishing aspects of control between patient and provisional controllers provides unique element of reciprocity that has received little attention in the control literature.

To varied degrees each of the four concepts, Locus of control, Relinquishment of control, Proxy control and Participatory control, address how people choose relinquishment of control based upon a perception that their innate ability to control is not as stable as external factors (Bandura, 1997; Miller, 1980; Reid, 1984; Rotter, 1966). Relinquishment of control to others is done as a means to control (Rothbaum, Weisz, & Snyder, 1982; Skinner, 1996). Internal control, or the belief that outcomes are the result of innate abilities and behaviors, is linked to learning under conditions that support personal skill development (Rotter, 1966). This is in contrast to external control, or the belief that forces beyond one's innate abilities have a greater influence over outcomes of personal

actions. External control is linked to learning under unpredictable conditions controlled by more powerful or competent others (Rotter, 1966), such as to provisional controllers. During stressful situations, as in this study when participants required hospitalization, people may perceive others to be more powerful or competent, and, as a result, better positioned to control unpredictable conditions. The unpredictable condition of biological recuperation that influenced *Regaining Control* was also noted among men after prostatectomy (Petry et al., 2004) and during the post-operative recovery process (Allvin et al., 2007). When conditions are unpredictable people relinquish control to provisional controllers.

Over a lifetime, individuals develop a usual pattern of behavior shifting between internal-external controls of reinforcement. Typically, that pattern tends to be more internal, or skill controlled, than externally controlled; individuals compensate according to situations without too much conscious effort (Reid, 1984; Rotter, 1966). As individuals age with chronic illnesses this typical pattern shifts towards more externally oriented control (Reid, 1984; Rotter, 1966). This vacillating interactive continuum between externality and internality requires individuals to recognize what can and cannot be controlled and the need to acquire help from others (Reid, 1984). This was labeled participatory control: a “process in which a person may increase their sense of control through their relationship with another” (Stirling & Reid, 1992, p. 204). Reid (1984) referred to a need for greater external control during time periods of crisis, a transitory acute loss of control. Yet, he did not elucidate loss of control, illustrate shift to external control, or identify how individuals recalibrate to former patterns of control or adjust to new patterns. The theory of *Regaining Control* fills this gap by proposing a series of defining actions seem-

ingly consistent with this view of how patients shift between internal and external control during 'crisis' and adjust to degree of control regained.

The influential role of provisional controllers was evident in three studies. One study examined how hospitalized older adults used patient-controlled anesthesia (Pellino, 1997); another study examined how they adjusted to hospitalization (Cicarelli, 1987); and, the third study focused on patients who were hospitalized for COPD exacerbation (Torheim & Gjengedal, 2009). Those with COPD reported that treatment compounded feelings of loss of control, which was eased when nurses explained the purpose and expected experiences of the treatment (Torheim & Gjengedal, 2009). In comparison to younger hospitalized adults, 'important' others significantly influenced older adults' use of patient-controlled anesthesia (Pellino, 1997). Likewise, Cicarelli (1987) found that powerful others influenced how older hospitalized patients adjusted to hospitalization. This latter study used questionable measurements. For example, the tool measuring patient adjustment was completed by hospital nurses not patients. As a result this was a proxy measure and in some sense provides additional evidence that perspectives of nurses were, perhaps, more powerful than of patients. Nevertheless, these findings overlap with the current findings that illustrate the broader natural influence of provisional controllers on how participants exercised or relinquished aspects and degrees of control. This suggests another, perhaps stronger, indication of that which Pellino narrowly demonstrated and Cicarelli and Torheim & Gjengedal found. What still remains unclear and needs further study are the attributes of provisional controllers that influence the behaviors of hospitalized older adults. For example, current findings illuminated examples of positive attributes, such as informal provisional controllers with insider knowledge, and of negative

attributes, such as formal provisional controllers with demeanors that participants perceived as disengaged. The relationship among current findings and those in this extant literature underscore the interactive roles that both patients and their provisional controllers have in the theory of *Regaining Control*.

Generally the control literature suggests that relinquishment of control is a choice based on perceptions of internal-external control of reinforcement (Bandura, 1997; Miller, 1980; Reid, 1994; Rotter, 1966; 1975; Skinner 1996). This choice to exercise or relinquish control is influenced by three psychological conditions: perceived degrees of efficacy, uncertainty of outcomes, and, the perceived difficulty level of skill development needed to achieve a desired outcome (Bandura, 1997; Jacelon, 2007; Miller, 1980; Skinner 1996). Participants in this current study did not always ‘freely’ relinquish control, instead; they *submitted* to external control. They were compelled to relinquish control or have it taken from them in order to have needed treatment for their illness or injury. During the first phase, *Transferring Control*, individuals may be unable to recognize their loss of control. To varied degrees, biological injury or illness, a ‘crisis,’ creates a need for provisional controllers to take control and for patients to *submit*. This yielding of control was a gap in the literature noted by Miller (1980), suggesting a greater complexity in relinquishment of control that warrants further study. The theory of *Regaining Control* suggests that provisional controllers, together with understandings of hospitals, and biological recuperation, are additional conditions that influenced how participants relinquished and worked to regain degrees and aspects of control.

There is limited literature about the role of provisional controllers as it relates to hospitalized patients. In part, this may be due to conceptual overlap between relinquishment of control and proxy control. Proxy control is an individual's choice to:

relinquish control over events to free themselves of the performance demands...because they have not developed the means to do so, they believe others can do it better, or they do not want to saddle themselves with the onerous responsibilities that personal control entails (Bandura, 1997, p. 17).

This phenomenon has been interpreted elsewhere as delegation of control to efficacious individuals (Skinner, 1996). This was evident when participants in this current study were *directing provisional controllers*. Unlike the Bandura's definition of proxy control, *directing provisional controllers* was not done because participants had no desire to expend energy on 'onerous responsibilities.' Instead, with returning energy from biological recuperation they influenced others to exert control on their behalf because they themselves had yet to regain the biological capability to be able to physically control. With this view, it seems hospitalized individuals perform a complex risk-benefit analysis, influenced by degree of biological recuperation, about how to exercise control, independently or by delegating to a proxy, to achieve a desired or needed outcome. When participants were getting physically better, they focused on *directing provisional controllers* before they were well enough to exercise control for themselves. Furthermore, there were varied periods of time that the participants experienced a considerable loss of physical control. During these periods they needed provisional controllers to take on the controlling role. This indicates a seemingly more complex relationship than the one Bandura suggested that an individual voluntarily redirects their energy to influence others. Rather current

findings suggest that a lack of energy caused by biological damage means patients cannot independently exercise physical control. Provisional controllers, who provide needed supplemental control, such as hospital workers who treat an individual's biological damage, influence how he or she works to regain control.

Additional findings in the literature both support and contradict the premise that individuals must recognize their need to voluntarily relinquish control to others (Bandura, 1997; Miller, 1980; Reid 1984). In a way similar to *consulting*, hospitalized older adults recognized the need to relinquish control as they processed from their 'usual way of being' to 'identifying' and then 'confirming' their health problem with professionals and then 'transitioned' to an unplanned hospitalization (Jacelon, 2004a, p. 223-554). 'Relinquishing control' has been noted among community-dwelling women who let go of control to examiners during pelvic exams in order to maintain their gynecological health (Grundstrom et al., 2011). However, current findings also illustrate how, at times, individuals do not recognize this need. Indicators from this current study illustrate normalizing of symptoms (Glaser, 1975). Perhaps this is done to maintain usual patterns of internal-external control. Examples included participants' initial denial, refusal, doubt, or inability to recognize that their biologically based loss of control requires hospital care. When this occurred, provisional controllers recognized and acted on their behalf. Similarly, individuals suffering heart attacks initially 'normalized their symptoms' and maintained the 'status quo' until activities were too difficult to continue, or family and friends intervened, and sought hospital care (Johnson & Morse, 1990, p. 128).

Defining the role function for the two groups of individuals involved in the theory of *Regaining Control* is needed and requires a reconceptualization of relinquishment of

control and proxy control. By essentially defining the same phenomenon, neither relinquishment of control or proxy control advance an understanding about what is being done with control that is relinquished. Untangling conceptual overlap between these two concepts can be accomplished by delineating agents of control. An agent of control is a group of individuals exercising control (Skinner, 1996). From this perspective, in the theory of *Regaining Control* the two groups that are agents of control are patients and provisional controllers. There are times when the patients are the agents for relinquishment of control; and, provisional controllers are agents for proxy control. If this is reasonable, then it is necessary to reconceptualize proxy control in order to address how provisional controllers act as agents of control. Ideally, provisional controllers provide a continuum of supplemental control to hospitalized patients giving ‘exactly’ the help patients ‘need and want’ at that exact time (Berwick, 2009, p. 558). The nuanced behaviors of the theory of *Regaining Control* demonstrate shared control that support this reconceptualized symbiotic relationship between relinquishment of control and proxy control. Furthermore, it suggests a complex relationship that requires a better understanding of how provisional controllers determine when to act as agents of control and when patients cede agency of control to them.

Findings from this study demonstrate the interactive relationship between participants and provisional controllers similar to participatory control that include an essential and unique element of reciprocity, a mutually beneficial relationship between patients and care-workers (Reid, 1984). Participatory control requires a social norm of reciprocal participation and cooperation in which care-workers inform patients and encourage their input. The theory of *Regaining Control* provides additional support for the reciprocal rela-

tionships between a patient and formal provisional controllers that was noted among nurse-resident dyads in a long-term care setting (Stirling & Reid, 1994). A novel finding was *directing provisional controllers*. Participants lead efforts of participation and cooperation when developing connections among formal provisional controllers. Although not the focus of this current study, findings did uncover nursing staff who expressed appreciation for participants who worked to develop connections. While other findings documented patient desire for similar connections, these patients wanted hospital workers to lead efforts to recognize and respect the individual patient (Sjodahl et al., 2008). Arguably, patients not only want, but need, formal provisional controllers to lead or provide opportunities for developing connections.

Evidently, the responsibility for creating and maintaining a social norm of participatory control rests with the hospital organization. Participants prioritized *Exercising “Wobbly” Control*, which was influenced by their understandings of hospitals and perceptions of hospital care priorities delivered by hospital workers. Current findings support a traditional understanding of hospitals - they are institutions that manage all aspects of patient care. With organizational attributes that must be regimented, hospitals impede individual patient freedom, in order to service many patients and constituents (Allshouse, 1993; Taylor, 1979). Similarly, another naturalistic inquiry found that patients believe it is difficult to modify the organization of the hospital given the large number of patients and limited financial resources (Penney & Wellard, 2007). Taylor (1979, p. 159) called this “depersonalization,” hospital workers’ inability to account for individual differences among patients in the hospital setting, that influenced how patients took on the patient role.

Behavioral patterns in the theory of *Regaining Control* do not fully align with documented assertions that depersonalization results in either a bad patient defined by their state of reactance or a good patient defined by their state of helplessness (Taylor, 1979). Almost completely devoid of data from the perspective of patients, Taylor proposed that bad patients complain to staff and demand attention; good patients comply, act passive, and learn helplessness. In contrast to another study that did not find evidence of the reactance behaviors described by Taylor (Raps, Peterson, Jonas, & Seligman, 1982), this current study identified behaviors similar to those noted by Taylor. However, the behavioral patterns of *Regaining Control* describe and explain a process of iterative patient behaviors in response to loss of control. It does not categorize behaviors according to value-laden labels of ‘good’ behavior and ‘bad’ behavior. One of the categorical behaviors, interactive *resisting*, was a response to hospital workers exercise of arbitrary control perceived to jeopardize control. Also, current findings do not support Taylor’s hypothesis that hospital patients initially resist hospital care and then comply. Instead, the *resisting* behaviors identified in this current study occurred when participants regained some measure of physical control and were done to protect their control regained or *Regaining Control*. Participants resisted *submitting* or *following orders* if they perceived potential harm to regained control or potential new or recurrent loss of control. When participants submitted or followed orders it was as a means to regain more control in order to get well enough and get out of the hospital. Similarly, *submitting* corresponds with instances in the literature in which hospitalized older adults relinquished control to ‘rely on authority of hospital staff’ for hospital care (Jacelon, 2004b, p. 32) and other patients ‘passively allowing themselves to be cared for by others’ after suffering a heart attack (Johnson &

Morse, 1990, p. 129). Instances of *submitting* occurred when participants were unable to control space-time and social surroundings rigidly controlled by the hospital organization. These instances support Taylor's (1979) proposed state of helplessness. Together, current findings and those in the extant literature challenge current trends to realistically deliver patient-centered care as if "every patient is the only patient" (Berwick, 2009, p. 560).

Theoretical Underpinnings for Patient-centered Care

Current findings and the related extant literature provide initial theoretical underpinnings to understand the hospitalized patient as 'the source of control' (IOM, 2001) relevant to the development of patient-centered care. There appears to have been no in depth exploration of what it means for the patient to be 'the source of control', how that source of control manifests, or how the patient as source of control influences patient-centered care. The theory of *Regaining Control* and related extant literature suggest that patient-centered care is an evolving shift from a paradigm of paternalistic-control to participatory-control. Organizational efforts on part of hospital workers are essential for this evolution.

A highly-regarded 241-page *Patient-Centered Care Improvement Guide* (Frampton et al., 2008) of strategies to promote patient-centered care seems to lack scientific rationales. One strategy, *Just Ask Campaign* (p. 81), encourages patients and family members to ask questions, and, yet, recognizes a culture shift is needed for patients and family members to develop this behavior: "...patients don't know what to ask. The initiation should be from the health care person" (p. 137). Patients expect hospital workers to be the initiators (Allshouse, 1993; Walker, 1993). Patients speak up about safety concerns

based on their perceptions of how much threat a concern poses and the behaviors of health care workers (Entwistle et al., 2010). Hospitalized patients are hesitant to express concerns because they lack understanding or fear retribution (Allshouse, 1993; Entwistle et al., 2010). Substantiating these are findings from the current study and related extant literature that suggest hospitalized patients need hospital workers to take and direct control reciprocal to degree and aspect of loss of control. Patients are not interested in shared-decision making when they are acutely sick (IOM, 2001). People expect to lose a sense of control and autonomy in the hospital (Allshouse, 1993) and to do as told by hospital workers (Waterworth & Luker, 1990). No participant in this study ‘freely’ wanted to be in the hospital and they expected the hospital to be a restrictive environment. When participants required hospital care it was because they perceived no other choice but to allow hospital workers to address biological damage that impaired their biological capability to successfully maintain usual patterns of exercising control.

The literature has not focused enough on one essential dimension of patient-centered care - physical comfort. “Physical care that comforts patients...is therefore one of the most elemental services that caregivers can provide” (Gerteis et al., 1993, p. 8). Physical care is a fundamental aspect of nursing care or basic nursing care. Yet in their meta-analysis of seminal nursing texts to define fundamentals of nursing care, Kitson and colleagues (2010) found, in descending order, strong to weak agreement in the following aspects of basic nursing care: safety, nutrition, elimination and personal hygiene; then rest/sleep, mobility; followed by communication and respiration; then respecting choice, sexuality, temperature control; and finally, comfort, pain management, privacy, and dignity. Furthermore, *The Journal of Nursing Scholarship* had a recent call for papers that

examine basic nursing care (vanAchterberg, 2013). When biological damage disrupts normal activities to the extent that hospital care is needed, patients need health care providers to provide supplemental control for what they themselves cannot control. *Regaining Control* suggests a pattern of patient behaviors based upon their degrees of loss of control or control regained that has important considerations for patient-centered care.

Principles of patient-centered care include: respect and dignity for patients, information sharing, and participation (Gerteis et al., 1993; Institute for Family-and Patient-Centered Care, 2013). Patient-centered care requires patients and their families to assume more active roles and responsibility as evidenced in current trends of shared-decision making. Shared-decision making has been identified as a compromise between two extremes of care delivery: traditional paternalistic or professionally driven care, and informed patient or consumer driven care (Berwick, 2009; Bernabeo & Holmoe, 2013). While current trends are to place the needs of the patient first (Berwick, 2009), it is unclear who has the primary responsibility for defining “needs” especially when the patient is hospitalized with unstable biological damage and “wobbly” control. Current findings are consistent with other researchers who addressed patients’ need for formal provisional controllers to provide sound authoritative orders (Boltz et al., 2010; Penney et al., 2007; Sjodahl et al., 2008; Waterworth & Luker, 1990). The specific finding of *following orders* is an important contribution concerning the interaction between patients and hospital workers. *Following orders* emphasizes the need for hospital workers, especially nurses and therapists, to explicitly teach or direct patients and their informal provisional controllers. Specific to the professional concern that initiated this current study, these ‘orders’ should include explicit instructions to maximize bladder control. A published quote from

a qualitative study about hospitalized older adults, who wanted to go home better, not worse, after hospitalization, demonstrates retrospective appreciation for *following orders* that encouraged toileting: “The nurse said ‘I’ll help you walk to the bathroom. You won’t use the urinal at home.’ It was an inconvenience but [the nurse] was doing the right thing” (Boltz et al., 2010, p. 384).

Since patients may be reluctant to participate in hospital care (Boltz et al., 2010; Waterworth & Luker, 1990), they need formal provisional controllers to lead shared-decision making, especially during the more acute phase of *Transferring Control*. When given the opportunity to provide input about their care, patients avoid a complete submission of self to care-workers (Reid, 1984; Stirling & Reid, 1992). Although shared-decision making improves quality of care, cost-effectiveness has not been identified. Patients who had more information about exercising control during hospitalization had better patient outcomes (Miller et al., 1989). They benefited from understandable and straight-forward information about treatments and schedules (Torheim & Gjengedal, 2009) or felt disadvantaged when information was not provided (Jacelon, 2003). In addition, ambulatory patients felt more in control when health care providers recommended and explained treatments (Alexander, 2010; Grundstrom et al., 2011; Harris et al., 2008). Despite these findings, hospital workers lack role models who effectively create an atmosphere for patient-centered care and shared-decision making (Ellers, 1993). Published frameworks demonstrate the complexities for systematically studying, enhancing, and routinizing shared-decision making (Bernabeo & Holmoe, 2013; Towle & Godolphin, 1999). This is a critical deficit in knowledge and practice given the fact that current findings about *learning* are similar to observational learning by which people learn how to

exercise control by observing others (Bandura, 1997). Hospital organizations have yet to systematically create a social norm that fosters participatory control.

The evolution of patient-centered care taking place requires health care providers to teach patients how to become true partners or true sources of control. Exemplars of patient-centered care in the literature initially begin with professionally defined problems that are population-based health concerns, such as diabetes, elective cardiac catheterization, and end-of-life care ([EOL] Bernabeo & Holmoe, 2013). These foci are driven by the “tri-aim” of health care: conserve cost while maximizing access and quality. Traditionally, patients have not been involved in all phases of health care transformation. National efforts are underway via the Centers for Medicare and Medicaid Services and the Congressionally supervised Patient-Centered Outcomes Research Institute, but are too nascent to evaluate effectiveness. Simultaneously, at the microcosmic level there are post-hospital discharge patient advisory panels

<http://www.beckershospitalreview.com/quality/10-guiding-principles-for-patient-centered-care.html> to capture and include patient perspectives in organizational efforts to provide patient-centered care. *Regaining Control* and the related literature demonstrate the need for health care providers to lead, teach, or coach (Frampton et al., 2008), patients to become ‘sources of control.’

For example, in the hospital setting, toileting activities do not accommodate the needs of individual patients (Clark & Rugg, 2005; Connor & Kooker, 1996; Dingwall & McLafferty, 2006; Nikoletti et al., 2004). In this current study, participants thought that toileting activities bothered hospital staff. This patient perspective converged with a nursing perspective that hospital nurses initiate toileting interventions based on staff conven-

ience (Connor & Kooker, 1996; Dingwall & McLafferty, 2006; Nikoletti et al., 2004). Occupational therapists (OTs) believed patients would be uncomfortable if supervised during an entire toileting activity, but contrary to this belief, their patients would have appreciated assistance (Clark & Rugg, 2005). This is similar to findings from this current study where participants felt toileting bothered staff. Participants avoided bothering the nurses and therapists by *concealing* new-onset UI. This finding is consistent with the *a priori* review of the literature that revealed containment and concealment strategies were the main strategies noted across care settings (Bayliss et al., 2000; Beber, 1990; Boblin & Skelly, 1999; Cooper & Watt, 2003; Dingwall & McLafferty, 2006; Tannenbaum et al., 2004; Wagg et al., 2005). Current findings and the extant literature suggest that nurses and therapists need to provide supplemental control to lead, teach, and coach hospitalized older adults about bladder control and toileting activities. The social norm of the hospital and the roles of nurses and OTs regarding new-onset UI and toileting require additional study.

Contribution to the Current Literature

The *a priori* literature review made the case that UI is a ‘professional problem’ (Glaser, 1998) for nursing. No other study that examined new-onset UI from the perspective of hospitalized older adults has been identified in the current literature. As such, new-onset UI deserved to be studied in order to identify how hospitalized older adults assigned it priority. At the start of this study an assumption was that the patient, significant other, or hospital worker may perceive new-onset UI to be problematic. This study identified that participants were concerned with more than just loss of bladder control. Participants assigned higher concern to broader aspects of loss of control. As a result, the

process by which participants responded to loss of control and worked to regain control are likely important to a broader population of hospitalized older adults, not only to those with new-onset UI. Finally, groups who take on control, provisional controllers, play an important role in how patients behaviorally shift control. By documenting how this focus population experienced loss of control, the theory of *Regaining Control* contributes theoretical groundwork that addresses the social and environmental factors previously identified as a gap in the UI literature (Palmer, 2004).

By identifying the participants' main concern of loss of physical, spatial-temporal, and social aspects of control, this study demonstrates how participants worked to resolve that concern in order to get well enough to go home. In doing so, the theoretical findings of *Regaining Control* offer a description and explanation about how patients regain control during hospitalization and how health care providers can assist patients in this process. Comparing extant literature with this study also offers an understanding about how the patient embodies being 'the source of control,' and could be useful in helping to operationalize this concept for providers and researchers. *Regaining Control* offers several contributions to literature, not only about UI, but also about control and patient-centered care.

Current findings contribute to the broader literature of control. The first is the elucidation of three aspects of loss of control during hospitalization. This provided the catalyst to study behavioral patterns that broadly addresses what was alluded to by other researchers. As a result the theory of *Regaining Control* offers a three-phase process of behaviors consistent with the theoretical literature that posited how individuals shift along a continuum of internal and external control during 'crisis.' The fact that research from

other substantive populations support current findings suggests that *Regaining Control* is a basic social process (Glaser, 1978) that is not unique to hospitalized older adults with new-onset UI. In particular, patients generally *submit* to health care providers in order to maintain or regain control. Lastly, unique findings include *directing provisional controllers* and a different view of *resisting* and *submitting* behaviors. According to the reviewed literature about patient-centered care, *directing provisional controllers* is likely a desired behavior that reflects the patient is engaged in care. Current findings suggest that *resisting* behaviors should not result in patients being labeled ‘bad’ (Taylor, 1972). Instead, these behaviors reflect a degree of control regained or a way of preventing a loss of control and should cause hospital workers to pause and reflect.

Findings contribute to the literature about patients being ‘sources of control’ and patient-centered care. This study provides a perspective grounded in data about how individuals transition to the role of a hospitalized patient. They do not always ‘freely’ give control to hospital workers. They transfer control not because they want to be in a hospital, but because they need to be in a hospital. Nevertheless, the theory of *Regaining Control* suggests that hospitalized patients have natural tendencies for shared-decision making that need to be recognized and fostered by hospital workers. During *Transferring Control* there is a condition of dependency on hospital workers. Whereas, during *Exercising “Wobbly” Control*, when patients are following orders, there is an opportunity for workers to coach them and their informal provisional controllers about shared-decision making. Last, findings support the characteristic of reciprocity as part of participatory control (Stirling & Reid, 1992). All of these provide inductive theoretical underpinnings for patient-centered care that have not been found elsewhere in the literature.

Summary

By describing and explaining how participants responded to loss of control, the theory of *Regaining Control* provides three important perspectives of control that have not previously been identified. These include: the action-oriented nature of control that patients identify as important to them, the process of control sharing between patients and provisional controllers, and the periods of acute and transitory change in control that occur throughout a period of illness or injury that necessitates hospitalization. A survey of the control literature found either no reference to, or only small indications of, the naturally occurring action-oriented control that was identified by the participants as important to them. Until the theory of *Regaining Control*, a description and explanation about the interactive process between individuals and recipients of their relinquished control (provisional controllers) was not identified in the literature. To some degree these current findings conflict with policy leaders who advocate for patients to control. There are unavoidable situations when individuals experience loss of control. Under these circumstances they simply cannot ‘freely’ give control. Instead, control must be claimed by provisional controllers. It is not practical that patients should be expected to freely give control to hospital workers. Instead, it is more practical to suggest that control be fluidly exchanged: taken as needed, shared when the patient is able and then handed off and reclaimed as biological recuperation commences and progresses. The suggestion that a reconceived codependent relationship of relinquishment of control and proxy control decreases overlap among these terms may create a better opportunity for empirical testing. Further study is needed to understand how to best facilitate *Regaining Control* to the fullest extent possible.

Chapter Six

Conclusion

In the face of an extensive body of nursing and medical literature about urinary incontinence (UI), there were no reported studies about the experience of new-onset UI from the perspective of the hospitalized older adult patient. By using Grounded Theory (GT) methodology, this study provides a theoretical framework to understand the main concern of hospitalized older adults with new-onset UI and how they work to resolve that concern. Hospitalized older adults with new-onset UI worry about loss of control – physical, spatial-temporal, and social. UI is but a small part of loss of control under concern. To address a broader concern over loss of control, participants did their best to work through the three-phase process of *Regaining Control*. Since the main concern of the participants was not new-onset UI, the emergent theoretical findings suggest a basic social process (Glaser, 1978; Glaser & Strauss 1967) likely relevant to other hospitalized groups of adult patients and perhaps other research areas where people suffer from acute debilitating conditions.

Strengths and Limitations

This is the first known naturalistic inquiry of new-onset UI from the perspective of hospitalized older adults. In their seminal work on GT methodology, Glaser and Strauss (1967) laid a foundation of ‘doubt’ for the traditional canons of judging theoretical findings, suggesting instead that many theories are developed without data as a means of support. The unique development of Grounded Theories requires tests of rigor that support the method. This credibility and rigor, or “believability” (Glaser, 1998, p. 236), make use of four criteria: fit, relevance, work, and modifiability (Glaser, 1992; Glaser,

1998; Glaser & Strauss, 1967). The reliability and validity measures used for deductive analysis are not applicable; although, fit was analogously used for validity (Glaser, 1998). Fit is achieved when the theory and all of its categories and properties represent or ‘fit’ the data. Relevance of a GT theory is achieved when the resulting theory is useful to, or ‘relevant’ to, those who will use the theory be it academics, practitioners, or members of a similar group to the substantive area from which the theory was developed. When readers identify with the main concern, it has “grab” (Glaser, 1998, p. 237). A GT study is said to work when the theory identifies the major behavioral patterns that participants exhibited as they worked to resolve their main concern. Finally, modifiability is achieved when theoretical findings are open to additional comparative criteria that might afford opportunities for varying or adding patterns of behavior (Glaser, 1992; Glaser, 1998; Glaser & Strauss, 1967).

The theory of *Regaining Control* achieves fit. This theory emerged from the data. Repeatedly, the problem of loss of control was noted in the data. Identification of the participants’ main concern, not the professional problem, is an essential methodological aspect of Grounded Theory methodology. The PI used GT methodology (See Chapter Three) to develop a theory of how older hospitalized adults with new-onset UI sought to resolve their main concern over loss of control. This systematic GT analysis ‘fits’ the data (see Appendix K for Examples of Coding and Theoretical Memoing) providing theoretical completeness (Glaser, 1992, p. 124).

Although not an explicit requirement of GT, multiple types of data were used in this GT study, including observed behaviors that were then discussed with participants. The PI performed eleven of the fourteen interviews during the hospitalization period

yielding data from the narratives and behaviors of the participants in the hospital environment. The presence of the PI in setting was critical to using GT methodology in this study as it captured behavioral patterns that participants did not always articulate. For example, during one field visit prior to a recorded interview the PI observed a participant trying his best to be respectful to a hospital worker. Yet, the volume of his voice raised and the intonation changed to be firm and pointed, “I was told I was off today,” as if simultaneously stifling anger. This observation provided data that the PI was subsequently able to use as support for a probing question that prompted the participant to reflect on the interaction. Data from this interview provided one instance among several used to identify an action resulting from an observed participant interaction and showing ‘fit’.

The broad main concern of the participants in this study is likely to have relevance with readers involved with hospital care. Incidents from multiple sources in the extant literature support the theory of *Regaining Control* - the core category, three phases, and their properties (See Chapter Five). Although the theory in its entirety was not evident in any single source, aspects of similar findings were found in a wide variety of studies reported. This suggests it is a basic social process that conceptually transcends the data of person, place, and time (Glaser, 1978; Glaser & Straus, 1967). Control found in the extant literature is clearly a professional concern in the field of nursing. Policy recommendations call for increased patient control (IOM, 2001) thus making patients and their provisional controllers stakeholders in the current trends of shared-decision making (Institute for Patient and Family Centered Care, n. d.). This theory has relevance for each of these groups.

The theory of *Regaining Control* ‘works’. It describes and explains most of the variation of behavior among the participants. When theoretical sorting was completed the methodological rule of “integrative fit” was met; a rule that posits that the world is socially organized in an integrated fashion and a grounded theorist’s goal is to discover the social organization (Glaser, 1978, p. 123). The categories and properties incorporated the generated substantive codes. Common behavioral patterns were identified from a range of individual data from participants with diagnosis’ that were similar to the demographic trends on the rehabilitation unit and an equal representation of men and women.

The setting of this GT study and the predefined professional problem that was the focus of the early phases of this study provide possible positivistic limitations: the setting, challenges with privacy, and pre-defined study materials. While this may delimit the application of the results to the focus population, it is very likely that these theoretical results are applicable to a much broader population. The modifiability of the current study makes further study possible with broader populations. Grounded Theory is a research method developed to provide opportunity for ongoing data collection, thus making the narrow nature of the focus population of this particular study of little concern. Future researchers can readily apply the knowledge gained from the theory of Regaining Control and modify it based on new data. Future data may come from other focus populations, such as hospitalized younger adults with new-onset UI, overall patients experiencing hospitalization, or even this same focus population but from a larger geographic area or over a longer period of time from hospital admission to post-discharge.

The inpatient rehabilitation setting of this GT study was selected to maximize recruitment efforts. Patients here were considered to be less frail than those on other acute

care units. As a result, the findings of biological recuperation may provide a specific view, or degree, of biological recuperation different from other inpatient units. Data drawn from other substantive areas might result in slightly different or greater variation in the data. For example, patients who experienced new-onset UI that resolved before transfer to the rehabilitation unit may completely forget episodes of UI. Recruitment on other inpatient units or the emergency department may identify patients with experiences where new-onset is more nascent, isolated, or transitory. This additional data may modify the Theory of *Regaining Control*. For this current study, the hospital-based organizational constraints limited access to these other units.

A few other constraints limited the PI's access to individual patients. Semi-private patient rooms, a common practice among most hospital units, limited the PI's ability to conduct private screening and interviews. Rigid and rigorous therapy schedules, although vital to patient recovery, posed some difficulty in timely interviews. Three participants chose post-hospitalization interviews as scheduling during the hospital stay was too difficult. While this resulted in retrospective data that did not capture the real-time reality of being in the hospital, it did provide real-time data that informed how participants were *Adjusting to the Degree of Control Regained* after hospitalization. Grounded Theory methodology incorporated this data that was initially viewed as a limitation. By comparatively analyzing the data and not forcing preconceptions these data quality issues became fortuitous instead of being detrimental as greater knowledge was gained about the process of *Regaining Control*.

Pre-defined study related materials identified and focused on a professional nursing problem to participants in this study. Although this might have led participants to fo-

cus on UI it did not appear to overly do so. This focus might have detrimentally caused two groups of eligible patients to reject participation. The first group are patients who did not view the professional problem of new-onset UI as worthwhile or had other pressing concerns; and then those who shared vivid details of their new-onset UI during screening, but did not want to revisit or detail their experience with the PI. This unavailable data may, or may not, have influenced the discovery of the theoretical findings. The modifiability of a GT study makes these two situations ones that can be taken into account with further study.

Implications for Practice

The theoretical contributions of *Regaining Control* have several implications for professionals involved with hospital care and health care policy. From the perspective of the main concern of the participants, the three phases illuminate the need for supplemental control from provisional controllers. During *Transferring Control*, provisional controllers need to know and understand when and how much control to take on in order to effectively provide supplemental control. A specific example, interchangeable indices (Glaser & Strauss, 1967), was informal provisional controllers recognizing when participants had some signs of a stroke. This underscores a need to advance practice and policy efforts to educate the public about the immediacy of seeking hospital care at first sign of a stroke. In addition, it is possible that formal provisional controllers, specifically nurses and therapists, who read these findings may evaluate their practice and develop greater empathy for older adults with new-onset UI (Jacelon & Dell, 2005). It would behoove these controllers to recognize that hospitalized older adults with new-onset UI try their best when *following orders*. Therefore, nurses and therapists must provide older adults

with new-onset UI, and their informal controllers, specific ‘orders’ for addressing bladder control. If and when *resisting* occurs, it is not necessarily reflective of ‘bad’ patient behavior. Instead provisional controllers must consider that this resisting protects control regained or prevents a new or recurrent loss of control. Formal provisional controllers need to present a responsive demeanor of willingness and ability to share control with patients and their informal provisional controllers. This may counter the commonly held concern among participants, which was about “bothering” the nurses and therapists. In turn, this may facilitate this second phase.

Similarly, findings have implications for hospital administrators, particularly those involved with risk management and quality improvement. At this organizational level, it is important that administrators evaluate if existing policies for assessment and management of new-onset UI are consistent with clinical guidelines and facilitate provision of ‘orders’ targeting bladder control. For example, the use of the “If ...then...” approach is useful (Gnanadesignan et al., 2004; Schnelle et al., 2003). Specifically, *if* a patient has UI, *then* a focused history is performed and the type of UI is determined and documented. In addition, hospital administrators should examine how the organizational behavior of the hospital facilitates or hinders how hospitalized older adults learn to exert returning control that fluctuates. More specifically, they might address how the institutional priorities create a social norm to facilitate participatory control. The final phase of the theory, *Adjusting to Degree of Control Regained*, has implications for formal provisional controllers involved in discharge planning, such as case managers. These individuals many benefit from understanding how participants reassigned control during the transition out of the hospital.

The theory of *Regaining Control* offers a process that federal policymakers and those in accrediting organizations should consider when making recommendations about patient-centered care and shared-decision making. The theoretical explanations about participants working to regain control may be broadly applicable to other hospitalized populations. The notion of reciprocity that emerged from theoretical findings and their relationship to the control literature (Bandura, 1997; Miller, 1980, Reid, 1984; Skinner, 1997) provides a dynamic illustration of shared control among participants and their two groups of controllers. However, this explanation is not entirely consistent with current policy recommendations that call for the patient to be the ‘source of control’ (Berwick, 2009; IOM, 2001). Practically, this cannot always be the case. Findings about the influence of provisional controllers on the process of *Regaining Control* support policy recommendations that family caregivers be included in hospital care and methods of training these caregivers be developed (Reinhard, Levine, & Samis, 2012).

From the perspective of the professional problem, the theory of *Regaining Control* has implications for two groups: researchers and practitioners involved in hospital care and researchers and practitioners contributing to UI clinical guideline development. Researchers and practitioners working in hospital care should examine treatment-related and worker-related factors that contribute to new-onset UI and discern if there are worker and unit variations that may be amendable to intervention. Researchers and practitioners specializing in UI policy should compare current guidelines to the three phases of *Regaining Control*. Both groups may examine unique and shared institutional characteristics that address the nosocomial nature of new-onset UI, such as participants attributing their bladder troubles to having indwelling urinary catheters or not wanting to bother the hos-

pital workers. The participants in this study did their best to learn when it was the best time to ask for toileting assistance (supplemental control), such as before or after therapy in the gym. As one of many patients needing supplemental control, when a participant did call for assistance, he or she had to wait for formal provisional controllers. Sometimes, the result was an episode of new-onset UI. Some participants avoided this wait-time if their informal provisional controllers helped them get back and forth to the bathroom. Others had these controllers bring name-brand diapers to conceal UI. This implies there is a need to align the two groups of provisional controllers to best supplement degrees and aspects of loss of control that may enhance bladder control. Since the a priori literature review identified new-onset UI as a professional nursing problem and the patient control literature exemplified how professional problems stimulated improvements in patient-centered care, nurses are the formal provisional controllers best positioned to lead efforts in this alignment

Recommendations

Based on findings from this study there are several recommendations for nursing research and education. Replication and expansion of this study in different hospital units may discover other patient experiences of new-onset UI for modification (Glaser, 1998). Pioneering patient-centered care hospitals, or specialty units, such as an acute care for the elderly unit, neurology unit, or urology unit, may utilize different plans of care, which influence the supplemental control provided by provisional controllers. It may be worthwhile to study cognitively impaired hospitalized older adults with new-onset UI given the fact that the a priori literature identified confusion as a risk factor for new-onset UI

(Kresvic, 1997; Palmer, 2002). Since a broader main concern was identified, this study may be replicated with hospitalized older adults, regardless of continence status.

The results of this study suggest that participant behaviors were influenced by their interactions with provisional controllers, biological recuperation, and their understandings of hospitals. Prospective research examining multiple perspectives is recommended. For example, consistent with the disentanglement of relinquishment of control and proxy control presented in Chapter Five, data collected from older adults and their provisional controllers from the time of admission to the hospital through to their transition out of the hospital may modify the theory of *Regaining Control* (Glaser, 1998). Future study should include the identification of the key attributes and behaviors of provisional controllers that influence how hospitalized patients work to regain control. Clusters of older adults and their provisional controllers could be studied from the time of hospital admission through to one month post-hospital. Any number of research methodologies, including Grounded Theory, could be used to develop a greater understanding of the concerns of provisional controllers, how they go about resolving these concerns and how provisional controllers view the care and supplemental control they provide for loved ones who are ill. This would address the recommendation that study of training methods and interactions among these two groups of provisional controllers is needed (Reinhard et al., 2012).

Given the original focus of this study, it is reasonable to suggest there is an opportunity to reconcile the professional problem of new-onset UI with the loss of control identified as the main concern of the participants. Findings suggest there is a “window of opportunity” for the development of an intervention that delivers clear ‘orders,’ instructions

and practical guidance, about new-onset UI and other losses of control to patients and their informal caregivers. A quality-improvement (QI) interdisciplinary intervention may be devised, implemented, and evaluated by nursing and other disciplines, such as physical and occupational therapy. In accord with the patient-centered care literature this QI process should encourage patient and family involvement. The intervention to be tested should initially address the discovered challenges that participants experienced while using the toilet, which appeared to be institutionally created barriers. For example, the inadvertent barriers created by the institutional milieu caused participants to tailor toileting times before or after therapy gym times, because they determined that toileting disrupted therapy routines. Improvement efforts might address how to unite the functional therapy goals with the goals of treatment for new-onset UI. It is important that the intervention incorporates the role of informal provisional controllers inasmuch as they emerged as influential to process. Investigation of how to best maximize and support their role before, during, and after hospitalization is needed.

The theory of *Regaining Control* provides a theoretical framework for the development of educational initiatives pertaining to shared-decision making. Recently, key competencies for shared-decision making have been proposed for physicians, patients, and the health care system (Bernabeo & Holmoe, 2013). Current findings suggest that similar competencies be devised for hospital workers and informal caregivers. Research is needed to discover methods about how to develop consistency among the practices of hospitals workers that will included asking patients about their priorities and coaching them to become ‘sources of control’ (Framptom et al., 2008).

Summary

Until this study, the perspectives of hospitalized older adults with new-onset UI were not known despite the extensive body of medical and nursing literature pertaining to UI. Although multiple clinical guidelines exist, none have included the perspectives of hospital patients. This naturalistic inquiry using Grounded Theory methodology discovered theoretical explanations of behavioral patterns grounded in data. The theory of *Regaining Control* explains how participants behaved to address their concern about loss of control and getting well enough to go home. The situation of new-onset UI was a distraction for patients but not a main concern. For those that achieved enough biological recuperation, it required them to organize their energy and direct provisional controllers, conceal UI, and resist following some orders in efforts to exercise bladder control. In some cases, new-onset UI required coping skills and strengths even beyond hospitalization and drew on participants' financial and social resources during hospitalization for those who purchased brand-name diapers. A salient summation by one participant, "[I] follow their [therapists and nurses] example and what they want me to do." Formal provisional controllers must be mindful of this and provide clear evidence-based instruction or 'orders', to older adult patients and their informal provisional controllers, about new-onset UI.

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Appendix A

Review of Clinical Guidelines for Urinary Incontinence

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
Fantl et al., (1996)	Multiple Improve the re- porting, assess- ment and treat- ment of UI; sys- tematize clinical practice; educate HCPs and lay- person; encour- age fu- ture re- search.	Adults in out- patient, inpa- tient, and LTC settings	Charac- teristics of differ- ent types of UI (e.g., transient, stress, urge). De- scribes a basic evalua- tion: H&P with pel- vic and rectal exams, PVR, urinaly- sis, blad- der re- cord, mental status exam, func- tional social assess- ments. Basic evalua- tion does	Three In- tervention categories: Behavioral; Pharma- cological; Surgical. Behavioral: Toileting: routine, scheduled, habit and prompted; Bladder retraining; PMEs, BI, biofeed- back, vagi- nal weight training, and pelvic floor elec- trical stimulation Contain- ment and conceal- ment strategies (e.g., ab- sorbent products) for chronic intractable	Uncertain di- agnosis; failure to improve, hematuria without infec- tion; presence of other co- morbidities (e.g., persistent difficult blad- der emptying)	Expert panel conducted a compre- hensive literature search and catego- rized find- ings as A=Contro- lled trials B=Clinica- l series C=Expert opinion	Ana- lytic focus is be- hav- ioral. Date d, but semi- nal work still cited by ma- jority of con- tem- po- rary guide lines and in the re- search litera- ture

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
			not in- clude special- ized tests: urody- namics, endo- scopy, or imaging. Indica- tions for advanced evalua- tion pro- vided.	urinary inconti- nence			
Inter- na- tional Con- sulta- tion on Incon- ti- nence (2000)	Produce and provide recom- menda- tions to all health- care profes- sionals for as- sess- ment and treat- ment of UI.	World- wide and across the life- span	Assess- ment in- cluded: validated question- naire, detailed PE, renal function, uroflow- flow- metry, urody- namics prior to surgery. If indi- cated: addi- tional urody- namics, pad test- ing, uri-	Algorithms provided for the ini- tial man- agement of UI in vari- ous popula- tions (e.g., men, women, frail eld- erly).		US AHCPR guidelines (Fantl et al., 1996)	Stres- sed re- sourc- e avail- abil- ity. As- sess- ment was the same as used by Fantl (1996)

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
			nary tract imaging.				
The Royal Aus- tralian Col- lege of Gen- eral Practi- tion- ers (2002)	Guide- lines for general practice	Indi- viduals with inconti- nence.	Clinical assess- ment should include: detailed general medical and GU history, charac- teristics of UI, other related symp- toms, fluid in- take, medica- tion use, environ- mental factors (includes care- taker); cogni- tion, and expecta- tions o treatment (personal goals/mo tivation). PE should	Inclusion of conti- nence advi- sors and physio- therapists in plan of care, and occupa- tional therapists if functional UI. Specific interven- tions for type of UI. Stress UI: weight loss, PRME, constipa- tion man- agement, electrical stimula- tion, re- moval of causative mediations. Urge UI: bladder training, biofeed- back, re- duce caf- feine in-	Refer if pain, hematuria, re- current infec- tion, prostate enlargement, significant PVR	Listed but did not detail source for Levels of Evidence: I (System- atic re- view of relevant RCTs) to IV (case, series or pre and post- testing) and O (opinion of respec- tive au- thority); and strength of recom- menda- tions: A (good evi- dence to include) to E (good evidence to ex- clude)	Guide- line sepa- rated popu- lations (e.g., men post- pros- tate sur- gery UI, over- flow related to BPH)

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
			<p>include neuro-logical, abdominal, GU, PVR, cough test, bladder diary, urine culture.</p> <p>Specific to older adults: assess for transient incontinence (DIAP-PERS mnemonic) and bladder function via cough stress test and urinary flow rate by direct observation. Also note cognitive status, mobility and dexterity.</p>	<p>take. Overflow UI: determine cause. Functional: prompted void and environmental modifications. For the dementia population: prompted/timed voiding is recommended.</p>			

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
Scot- tish Inter- colle- giate Guide lines Net- work (SIGN , 2004)	Provide PCPs with tech- niques to as- sess, treat and possibly refer patients with UI	Scot- land: adults who visit PCP	Risk fac- tors de- scribed in detail. UI Assess- ment in- cludes clinical history (medica- tions, bowel habits, function, toilet access, sexual dysfunc- tion, and QoL) that can be supple- mented with question- naires, pelvic floor* assess- ment, urinaly- sis*, PVR*, flow rate, DRE*, bladder diary*, pad tests)	PFME; bladder retraining; fluid man- agement; contain- ment prod- ucts; phar- macologi- cal therapy	Failed surgical repair or con- sideration of surgical repair (e.g., surgical correction of pelvic organ prolapse); ele- vated PVR.	SIGN ^b SIGN 1++ (high- quality meta- analysis, systemic reviews of RCT) to 4 (expert opinion)	No men- tion of tran- sient UI (*) items under assess- ment have been listed as pri- mary assess- ment criteria in all the other guide- lines re- viewe d Guide- line devel- op- ment in- cluded input

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
							from lay per- sons. Label: use with cau- tion since over 7 years old

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
				<p>ered “non-therapeutic interventions” and should only be used (1) as a temporary strategy while treatments are being determined or are under way and being evaluated; (2) an adjunctive strategies to other treatment strategies; (3) long-term management for UI after other options explored.</p> <p>Appropriate indications for indwelling urinary catheters include: chronic urinary retention unmanage-</p>			

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
				able by other means (e.g., straight catheteriza- tion sched- ule); altera- tion in skin adversely affected by urine; dis- tress caused by bed/clothin g changes (e.g., end of life care: or when women express this as pre- ferred. Advance treatment may in- clude sac- ral nerve stimulation			
Amir et al., (2008)	De- scribe the compo- nents of urody- namics for evalua- tion of	Implicit: across the life span	Urody- namics are not indi- cated for conser- vative treat- ment of UI.	Urody- namic exam	NA	Used the schema of the Cana- dian Task Force on Preventive Health Care (2003): Levels for	Evi- denc e of spe- cific com- po- nents of UI is

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
	urinary tract dysfunc- tion		Indi- cated if initial H&P is incon- clusive; for sub- jective com- plaints that do not match objec- tive findings; for fail- ure to improve UI; be- fore clinical trial/ surgical inter- vention			evidence included I, II1, II2, II3, III) and grade for rec- ommenda- tion in- cluded A (good evi- dence to include) to E (good evidence to ex- clude) and I (insuffi- cient quantity or quality or evi- dence to recom- mend).	con- flict- ing due to con- tro- ver- sies re- gard- ing uro- dy- nami- c test- ing (i.e., arti- ficial test- ing does not re- flect nor- mal uri- nary tract activ- ity of daily life. No de- tails about

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
							the litera- era- ture searc h or proc- ess of rat- ing the evi- denc e.
Dowli- ng- Cas- tronov o & Brad- way, (2008; 2012)	Provide an evi- dence- based practice protocol for use by nurses in hos- pitals	Hospi- talized older adults (≥65 years of age)	Docu- ment conti- nence status and per- form detailed assess- ment and col- laborate with in- terdisci- plinary team mem- bers De- termine appro- priate- ness of indwell- ing uri- nary catheter,	Behavioral treatment strategies outlined as general and UI type specific.	Presence of UI. Collaborate with interdis- ciplinary team to determine UI type and etiol- ogy.	Stetler et al., 1998: Level I – VI with I = system- atic re- views and VI = opin- ions of respected authori- ties/conse nsus pan- els.	Al- though the target popul ation is hos- pital- ized older adult s the au- thors note that little re- searc h from the hos- pital

GUID LINE Author	OBJEC- TIVE SCOPE	TAR- GET POPU- LATION	ASSESS	INTER- VENTION	CRITERIA FOR REFERRAL to SPECIALIST (e.g., urologist)	EVI- DENCE RATING SCHEME	COM MEN T
			if pre- sent, accord- ing to WOCN (1996) stan- dards				set- ting was avail able.

Note: Although, many of the guidelines included surgical interventions, these are considered beyond the scope of this dissertation proposal and, therefore, not included.

Abbreviations used in table are listed in alphabetical order:

BI = bladder inhibition

BPH = benign prostatic hyperplasia

CCS = containment and concealment strategies

DRE = digital rectal exam

FI = Fecal Incontinence

GI = gastrointestinal

GU = genitourinary

H&P = history and physical

HCPs = health care providers

ICI= International Consultation on Incontinence

LTC – long term care

NA = not applicable

NCC-AC = National Collaborating Centre for Acute Care

NCC-WC = National Collaborating Centre for Women and Children

NICE = National Institute for Clinical Excellence

OAB = overactive bladder

PCPs = primary care providers

PE = physical exam

PE = physical exam

PFME = pelvic floor muscle exercise

PFMT = pelvic floor muscle training

PMEs = pelvic muscle exercises

PVR = post-void residual

RCTs = randomized clinical trials

SIGN = Scottish Intercollegiate Guidelines Network (SIGN)

UI = urinary incontinence

USAHCPR = United States Agency for Health Care Policy and Research

WOCN = Wound Ostomy Continence Nursing

^a Canadian Task Force on Preventive Health guidelines available at <http://www.ctfphc.org/>

^b SIGN guidelines available at <http://www.sign.ac.uk/guidelines/fulltext/50/index.html>

Appendix B

Transient/Acute Urinary Incontinence

Possible Causes of Transient Urinary Incontinence
Delirium
Infection (e.g., Urinary tract)
Atrophic urethritis or vaginitis
Pharmacology (e.g., diuretics, anticholinergics)
Psychological disorders (e.g., depression)
Endocrine disorders (e.g., diabetes)
Restricted mobility (e.g., post-operative)
Stool (fecal) impaction

Adapted from Resnick & Yalla (1985)

Appendix C

Established UI

Type	Definition
Stress UI	<p>An involuntary loss of urine associated with activities that increase intra-abdominal pressure. Symptomatically, individuals with stress UI usually complain of small amounts of daytime urine loss occurring with physical activity/ increased intra-abdominal pressure (e.g., coughing, sneezing). More common in women, but also can be found in older men after prostate surgery.</p> <p>Genuine stress incontinence is urine leakage, in the absence of bladder contraction, observed during urodynamic testing. (Fantl, et al., 1996; Abrams et al., 2002)</p>
Urge UI aka Detrusor Instability, Overactive bladder	<p>An involuntary urine loss associated with a strong desire to void (urgency). In addition to urgency, signs and symptoms of include urinary frequency, nocturia and enuresis, and UI of moderate to large amounts. Age-related bladder changes predispose older adults prone to this type of UI.</p> <p>(Fantl, et al., 1996; Abrams et al., 2002)</p>
Overflow UI	<p>An involuntary loss of urine associated with over distention of the bladder, which may be caused by an underactive detrusor muscle and/or outlet obstruction leading to over distention and overflow. Individuals often complain of frequent, con-</p>

	<p>stant, or post-void dribbling, urinary retention or hesitancy, urine loss without a recognizable urge, or an uncomfortable sensation of fullness or pressure in the lower abdomen. A common condition associated with this type of UI is benign prostatic hypertrophy (BPH).</p> <p>(Fantl et al., 1996)</p>
Functional UI	<p>Involuntary loss of urine associated with non-genitourinary factors, such as cognitive or physical impairment(s), resulting in an inability to be independent in toileting activities. Acute physical or cognitive impairment(s) can reduce a person's ability to recognize voiding signals, find an appropriate place for voiding, or be physically capable of maintaining continence. When placed in an acute care setting, these individuals are challenged by the change in the environment making the voiding process too complex.</p> <p>(Fantl et al., 1996)</p>

Appendix D

One-page information sheet for nurses

Information for Inpatient Rehabilitation Staff about the
Study of New-Onset Urinary Incontinence in the Hospitalized Older Adult Population

Annemarie Dowling-Castronovo is doctoral candidate at the College of Nursing, Rutgers, the State University of New Jersey and is also an Assistant Professor of Nursing at the Evelyn L. Spiro School of Nursing, Wagner College. She is conducting a study about new-onset urinary incontinence – which is urinary incontinence experienced during hospital admission by a hospitalized older adult who was continent at time of hospital admission and experienced no urinary incontinence within 6 months prior to hospital admission.

You will see her on the inpatient rehabilitation unit (X/Y). She will need the staff to assist in the recruitment of patients. For example, staff nurses will ask cognitively intact patients over the age of 65 who currently experience UI, “Did the leaky bladder start in the hospital?”, and if the patient states, “yes”, then the nurse asks if (s)he would like to participate in this study. The staff nurse will also ask patients who are continent if they experienced UI at any time during the hospitalization, “Did you ever have trouble with your bladder control when you were in the hospital?”, and, again if the patient states, “yes”, then determine their interest to participate in this study.

Regardless of the patient’s response to the staff nurse’s query, the staff nurse will ask the patient’s permission to leave an informational flyer, which is found on the next page.

Once the patient expresses interest to participate in this study then Annemarie Dowling-Castronovo will be responsible for:

- explaining the study to the patient and determining eligibility based on inclusion/exclusion criteria: Inclusion: patients at the inpatient rehabilitation setting; age of 65 years or older; able to verbally communicate in English; cognitively intact; agreement to participate; continent - no sign or symptom of any amount of involuntary loss of urine - at time of admission to hospital as reflected by hospital documentation (e.g., nursing and medical admission documentation) and reported by the patient, and continent for six months prior as reported by the patient; and at least one episode of UI - involuntary loss of any amount of urine - during time of hospital admission as reported by patient and/or hospital staff. Exclusion: patients with indwelling urinary catheters at the time of recruitment;
- obtaining their informed consent;
- arranging time for the interview to take place;
- conducting the interview; and
- performing data management and analysis.

Appendix E

Informational flyer

Are you over the age of 65?

Did you have trouble with bladder control in the hospital?

If you answered YES to both questions you may be eligible to participate in a research study. As a participant you will be interviewed by a nurse who is a doctoral student. During the interview the nurse will ask you to talk about your experience with bladder control in the hospital.

All information will be confidential.

If interested, please contact:

Annemarie Dowling-Castronovo, RN, Doctoral Student,
College of Nursing of Rutgers, The State University of New Jersey,
917-239-0841

Appendix F
**NEW ONSET – URINARY INCONTINENCE
IN HOSPITALIZED OLDER ADULTS
CONSENT FORM**

You are invited to participate in a research study that is being conducted by Annemarie Dowling-Castronovo, who is a doctoral candidate at the College of Nursing at Rutgers, the State University of New Jersey in Newark, New Jersey. The purpose of the research is to understand how a new leaky bladder affects older adults in the hospital. The goal of the study is to learn more about bladder control in order to help other older adults.

Approximately 10 to 20 participants age 65 or older will participate in the study, and each individual's participation will last approximately one (1) hour.

Participation in this study will include: Annemarie Dowling-Castronovo will interview you at your convenience and review your hospital records. She will ask you for some personal information, like your age, to complete a form that will take about five (5) minutes to complete. Then, she will ask you questions about how the new bladder leakage affected/affects you. This interview will last about one (1) hour and will be audio-recorded. Ms. Dowling-Castronovo will also take notes to describe what is happening on your unit during the interview. For example, she may take notes about the environment of the hospital. At a later date, Ms. Dowling-Castronovo may speak to you again if more information is needed. This is not an experimental study; there are no experimental procedures or medications involved, and, therefore, there is no alternative procedure or treatment.

This research is confidential. Confidential means that the research records will include some information about you, such as your age, medical history, and personal concerns about your bladder control. In addition, this information will be stored in such a manner that some linkage between your identity and the response in the research exists. The way this information will be kept is by assigning you a participant code. Your name will not be kept on the information. All coded information will be in a locked file accessible only by Ms. Dowling-Castronovo.

Page 1 of 4

Participant's initials _____

Only Ms. Dowling-Castronovo, her research supervisors, and the Institutional Review Board at Rutgers University will be allowed to see the coded information, except as may be required by law. Your name will not be used in any publication or presentation work that results from this study, unless you want it to.

If you participate, there may be small risks. For example, sometimes patients become tired when they have visitors. If this happens the interview will be stopped immediately. Sometimes when patients have visitors, they have signs of distress or discomfort, such as pain. Again, the interview will stop immediately and the hospital staff will be notified immediately. If exhibit behavior that may jeopardize your well-being, such as hiding prescribed medicine the hospital staff will be notified even if you object.

You may experience feelings of embarrassment when talking about urine leakage. To make sure this feeling does not happen the investigator, who is an experienced nurse, will talk to you in a private setting that you find the most comfortable. It is possible that talking about bladder trouble may help you. The information you will share will help health-care professionals understand more about bladder problems that start in the hospital setting. This may help them to give better care.

Participation will not result in increased medical costs for you.

Your participation in this study is entirely up to you. You may refuse to participate or may withdraw from the study at any time without affecting your care. If you choose to withdraw you have the right to request that any information given to Ms. Dowling-Castronovo is not used at all. You have the right to ask questions now or at any time.

If you have any questions about the study or study procedures you may contact myself at ammcaz@pegasus.rutgers.edu or 917-239-0841 or [NOTE: the actual consents included the setting-specific authorized contact approved by the two IRBs; removed from this publication to maintain confidentiality].

If you have any questions about your rights as a research participant, you may contact at any time the [NOTE: the actual consents included the setting-specific IRB contact information approved by the two IRBs; removed from this publication to maintain confidentiality]

You will receive a copy of this consent form for your records.

Upon your request the group results of this research will be provided.

The investigator who has explained this form to me has explained all of the conditions that would have excluded me from being in the study.

Sign below if you agree to participate in this research study:

Print Participant's Name

Participant's Signature and Date

Annemarie Dowling-Castronovo

Investigator's Name

Investigator's Signature and Date

Investi-

Cell Contact: (917) 239-0841

Audio/Videotape Addendum to Consent Form

You have already agreed to participate in a research study entitled: *A Grounded Theory Study of New-onset Urinary Incontinence in Hospitalized Older Adults* conducted by Annemarie Dowling-Castronovo. You are being asked for your permission to allow her to audiotape the interview as part of that research study. You do not have to agree to be recorded in order to participate in the study.

The recording will be used for analysis by Annemarie Dowling-Castronovo. She will listen, transcribe, and analyze the interview. The recording and transcript will not include your name and will be assigned a code to protect your identity. All information will be stored in a locked file cabinet accessible only by Annemarie Dowling-Castronovo. All transcripts and audio recordings will be destroyed three (3) years after completion of the study.

Your signature below grants Annemarie Dowling-Castronovo permission to record you as described above during participation in the above-referenced study. Annemarie Dowling-Castronovo will not use the recording for any other reason than that/those stated in the consent form without your written permission.

Participant's Name

Participant's Signature and Date

Appendix G

 ID _____
 Date _____
 Site _____

Demographic Questionnaire

1. Year of birth _____
2. Sex: _____ Male _____ Female _____ Transgender
3. Ethnic background _____
4. Country of Birth _____
5. Highest grade completed

Grammar School	High School	College	Trade School
----------------	-------------	---------	--------------

 (describe)

_____ 1	_____ 9	_____ 13
_____ 2	_____ 10	_____ 14
_____ 3	_____ 11	_____ 15
_____ 4	_____ 12	_____ 16
_____ 5		
_____ 6		
_____ 7		
_____ 8		

Graduate School
 _____ (describe)
6. Lifetime occupation (s)

7. Marital Status:

_____ Never married	_____ Married	_____ Widowed	_____ Separated	_____ Divorced
_____ Life partner				
8. Date of hospital admission _____
9. Date of admission to inpatient rehabilitation _____
10. Admitted from

_____ Private home or apartment	_____ Nursing home	_____ Assisted Living
_____ Other (describe)		
11. Approximate Annual Income _____
12. Current payment sources for hospitalization:

13. Medical Diagnoses:

14. Surgical History:

15. Medications:

16. Environment:

☐ Private room

☐ Semi-private room

☐ Number of beds if greater than 2

Describe access to and the environment of bathroom facility:

Other environmental notes:

Appendix H
Summary of demographics

Mean Age	Mean 75.71 years Range 68-89 years
Gender	7 Men 7 Women
Ethnicity	European American Irish African American Jewish-American American
Marital Status	3 Widowed 7 Married 1 Single 3 Separated/Divorced
Education: Highest Year/Degree Completed	Range: 10 th grade to Graduate degree 3 Completed high school 1 Completed four-year college 1 Complete graduate degree Missing data for four
Lifetime Occu- pations	Parent Homemaker Business Office manager Construction
Reason for Hos- pitalization	7 CVA 5 Orthopedic conditions 1 Cancer 1 Cardiac condition
Length of stay in hospital prior to admission to in- patient rehabili- tation unit	Mean 5.89 days; Range 2-22 days Missing data for two participants
Days on in- patient rehabili- tation unit at time of interview	Mean 6.62 days; Range 4-23days Three participants were interviewed post-discharge as per their preference

Appendix I
Initial Interview Guide

I. Introductory Comments

Hello, how are you?

I would first like to start by thanking you for participating in this study. As you are now aware, the purposes of this study is to gain a better understanding of new-onset urinary incontinence – a new leaky bladder – that some older hospitalized adults experience. I will be asking you some questions that may not be easy to answer. I encourage you to answer to the best of your ability. There are no wrong answers. If at any point you become distressed or just wish to stop – the interview will be stopped.

Do you have any questions?

II. Statement of Confidentiality

I will be tape recording this session in an effort to maintain the integrity of your dialogue. I will assign a code to the recoding to protect your identity. Only my research supervisors, the Institutional Review Board at Rutgers University, and I will be allowed to access the coded information, except as may be required by law.

III. Corroboration of Demographic Data

[To save the time and effort of the participant the investigator will look for information from the hospital record to complete the demographic sheet. This information will be corroborated with the participant. Examples of questions:]

Is this information correct?

Is there anything else that you think is important for me to know?

II. Experience with new-onset UI

Tell me about the first time your bladder leaked/you felt you lost control of your bladder in the hospital.

Probes:

What happened when your bladder leaked?

What did you do?

Who was around when it happened?

Who did you talk with about it?

How did/do you feel?

What did/do you think caused the leak?

III. How is your bladder now?

IV. Ending the Interview

Ask if there is anything else that you wish to share? What do you think the future holds for you? How has this been to discuss your leaky bladder?

Complete with a brief summary of main theme(s)/point(s) and ask the participant to verify or clarify. Note: Always explore interactions with environment. Always clarify and/or explore unclear sayings.

Appendix J

How interview guide, probes, evolved

Experience with new-onset UI

What it is like for you to talk about this?

What would happen if you were in this situation again? How would you handle the situation? How is that different from what happened?

If the participant does not remember or states has a poor recall of events then:

What happens when you forget details?

What is your experience with forgetting details?

Tell me what you think about forgetting details.

New-onset UI in comparison to other experiences/situations in the hospital.

How does/did the bladder leakage compare to other situations you experienced while hospitalized?

Knowledge

During the episode(s) of new-onset UI and _____ (other situations if specifically mentioned), how did you learn about it? How did you learn to deal with it?

If participant had prior hospitalization(s)/insider knowledge then ask:

☐ How did your prior hospitalizations influence how you dealt with this hospitalization?

☐ How did having _____ (fill in type of knowledge) influence how you dealt with this hospitalization?

If a participant did not have prior hospitalizations(s)/insider knowledge then ask:

☐ How do you think this experience in the hospital would affect how you deal with another?

Degree of Conforming

Specific to new-onset UI and _____ (other situations previously mentioned) describe How you interacted with staff to meet your needs--getting up to the bathroom, getting ready for PT,

What helped you get your needs met, what barriers did you encounter?

How is your bladder now?

Ending the Interview

Before I leave, is there anything else you want to tell me about your experience with bladder leakage?

Appendix K – Examples of coding and theoretical memoing

Incidents in the data: Quotes/field notes - open coding	Conceptual	Property	Category
<p>“I get up so early at 5:30 AM.”</p> <p>“So if you weren’t able to use the walker, they would bring the com-mode to you ...”</p> <p>“They have so many to deal with”</p>	<p>Institutional routines</p> <p>↓health status</p> <p>Social milieu</p>	<p>Loss control of time</p> <p>loss of body/space control</p> <p>Loss control of social network</p>	Losing Control
<p>“As I get ready to get off the bed, I feel funny. My head is numb – whole ground is a whirlpool and the walls are going around. I was like paralyzed. I couldn’t manage. How I did, believe me dear, I don’t know. I went to the bathroom and did what I had to do. Then I went over to the telephone and called my daughter and said, ‘Look I am calling up the ambulance, I don’t feel good at all.’ They [EMTs] came. They checked me over and said, ‘We’re going to have to take you to the hospital.’”</p> <p>“My daughter is taking care of my husband [with Alzheimer’s]”</p>	<p>Body changes</p> <p>Paralyzed; unable to manage</p> <p>Denial</p> <p>Doing what had to/usual</p> <p>Calling loved one; notifying;</p> <p>formal help</p> <p>assigning jobs</p> <p>taking help/given help</p> <p>being a patient</p> <p>having responsibility</p> <p>Patients need to/are responsible to call/wait for</p>	<p>Loss of body control</p> <p>Pushing to do usual routine</p> <p>Informal consulting</p> <p>Formal consulting</p> <p>Role adjusting</p>	Transferring Control

<p>“daughter took fish”</p> <p>“name and date of birth”</p> <p>“have to go to therapy”</p> <p>Noted data on bulletin board on unit Majority of falls occurred when patient did not call or did not wait for assistance – [Field notes]</p> <p>“I had no choice, you have to be allowing of them [nurses] – to take care of you.</p>	<p>assistance</p> <p>Obligatory Responsibility</p> <p>perceiving no choices; allowing</p>	Submitting	
<p>“...then [nurses] wheel you into the BR and you would go.”</p> <p>...now he can tell when he can go. Calls for assistance. Field notes from what RN said</p> <p>“I do all the exercises and everything that they want me to do.”</p> <p>“And I said to the nurse - when you bring the commode back to the bathroom - could you lock it?”</p> <p>“Easy to pull up pull down and change. Pro-</p>	<p>relying on nurses</p> <p>Calling for assistance</p> <p>Doing/exercising as staff wants</p> <p>Asking/Directing</p> <p>Control space</p> <p>Lessen bothering staff</p> <p>Being a good patient</p>	<p>Following</p> <p>Following orders</p> <p>Following orders</p> <p>Negotiating</p> <p>Concealing</p>	Exercising Teetering Control

<p>protect the environment [from UI]: protect bed, take away all that unnecessary work of mopping up the bed. I am not guilty. I am not lazy all the time. Pee-pee in bed means the patient is lazy”</p>			
<p>“I called for the girls and two girls came and they were chit chattin. And I said, come on stopped talking, I have to go to the bathroom [tone of pleading]. Don't stand there chit chattin. You say you don't want me to go by myself and call for help. So let's go [tone more firm and pointed]”</p>	<p>Calling</p> <p>Support needed Pleading; BoHW reminding/referencing the rule demanding</p>	<p>Negotiating</p> <p>Behavior of controller</p>	<p>Exercising Teetering Control</p> <p>Contextual Condition</p>
<p>Went [to BR] upstairs [on unit], because once you were in rehab - I don't think they wanted to be bothered with ...I think maybe once I had to go to the BR.</p>	<p>Timing toileting around PT routines avoid bothering interpreting</p>	<p>Following Learning</p>	<p>Exercising Teetering Control</p>
<p>...described having a physical therapy session sooner than anticipated after lunch and was frustrated that even with pain and having an intensive morning session with a first walk the physical</p>	<p>Unmet expectation</p> <p>Reaching tolerance limit</p> <p>milestone</p> <p>Past experience</p> <p>Different from past</p>	<p>Loss control - timing submitting</p> <p>Following orders</p>	<p>Transferring Control</p> <p>Exercising Teetering Control</p>

therapist still wanted to do therapy. In the past she's been told to bear with pain but seem to be frustrated that this went beyond bearing it. [Field notes]			
“The fall was during the day - in the bathroom. I was there with my occupational therapist and he was showing me safety in the bathroom, right before I clunked by that fall.. you could hurt yourself. I fell he was there, I fell. They took x-rays and MRI'S the hospital went berserk... I was telling them I'm okay. They also surrounded me and gave me tests. I said guys you're wasting your time I've hurt myself worse when falling at home.”	<p>falling physical support teaching/learning</p> <p>recognize danger/teetering high support – no change in control; BoHW; Negotiating; Resisting/Negotiating</p>	<p>Loss of control – body/space Following</p> <p>Formal consulting submitting</p>	<p>Losing Control</p> <p>Transferring Control</p> <p>Exercising Teetering Control</p>
“And if you want to do that [go home instead of in-patient rehabilitation] then you have to sign yourself out. You don't want to do that, because you'll be back here. I'm glad I did go to rehab. I would've never been able to	<p>Unrealistic want Professional cannot endorse; learning consequence of bad choice Explicit reasoning/directions Reflecting on unrecognized lack of control/unrealistic wants</p>	<p>Inappropriate exertion of teetering control Learning</p>	<p>Exercising Teetering Control</p>

manage.”			
<p>So now I have to go to the BR and I went sliding. So after that, I had to check that all four wheels were locked... I would have to go with my foot [made motions] to make sure it was in a locked position then I would go like this [gestured that she would shake the commode]. So to me - to go to the BR was a hassle. You know?”</p> <p>Normally, I would go to the BR before I go to rehab and then when come back - go again.</p>	<p>Loss of control – space /Learned from experience Got used to checking secure =control Still a hassle Toileting around unit routines/timing void</p>	Getting Used to It	Adjusting to Degree of Control Regained
“...once I was good with the walker...	Health status (individual force/context)	Recuperation	Contextual Condition
<p>“...tell me right away you should not have any pressure on you.” retelling what PT told him</p> <p>“...they had was a commode over the toilet. The nurses that would bring the other patients into the bathroom - they wouldn’t lock the commode. They wouldn’t lock the commode.”</p> <p>And they never did.</p>	<p>Getting permission Explicit directions physical environment (Institutional force/context); Many nurses/patients Safety Nurses’ response</p>	BoHWs > Behaviors of Controllers	Contextual Condition

[lock the commode]			
Knew from last time - wears brand name diapers "just in case" no one can get to her in time.	Prior knowledge	Understandings of hospitals	Contextual Condition

Examples of Memos Pertaining to Core Category

Remembering routines? Anticipating?

02/12/2011 this is a characteristic of institutional routines (substantial code)? Not so sure yet ... this is the participant verbalizing awareness of these routines refers to the quote there's the nurse; institutional routines refers to how the care takes place/or is perceived.

03/23/2011 Conforming - go with the flow?

04/01/2011 been thinking and thinking see March/11 loose notes. Participants are describing how they conform to institutional routines/care. I don't think is navigating. To me navigating means they feel "in charge" or empowered to direct care - which some may feel and, in fact, have behaved. Others conform - yield to, give in to. I fear that the study is too similar to JPR's. However, the main concern is getting out/home. Don't recall that being the main concern in the NH setting. Therefore, in order to accomplish that main concern they perceive that conforming to rehab/hospital routines will make that happen. When they feel too sick -they could care less, but as they gain strength the desire to return home is stronger and they will do what they need to do = conform. At this time really thinking to merge institutional routines with CC. Also thinking of re-naming the code institutional routines to **conforming to institutional routines/care**. Thinking that nursing and therapy-ing are characteristics of institutional routines/care

04/07/11 hospital context main concern is getting out going home to loved ones; to physical space; to pets. Conforming to institutional care routines (gym time; rest time); if toileting is not part of routine – avert. ICS to help/stay longer or conform – toilet when can and wear products (this is my professional concern? But this is how they behave)

04/15/11 OOB to BR ad lib when cleared to be independent with walker - like a milestone others have not mentioned – others have been too dependent?

05/04/2011 Changed code name from institutional routines to Conforming to institutional care - I view this as a continuum conforming - averting. At one point in the "doodle" dia-

gramming - I had navigating - after much thought and more constant comparative analysis I changed this to conforming. Navigating has a greater connotation of having **control** ... and the hospital environment is a different social context - one that a person has less **control**.

05/04/2011 Should it be institutional care or hospital care - leaving as institutional since more conceptual again thinking of properties/characteristics of this CC: conform vs circumvent. From my written model - deal with containment product since it allows to conform to rehab routines - attached to "new norm" - going to look at that code next.

05/23/2011 Meeting with Dr. Robinson: Changed title from "Conforming to Institutional Routines" to "**Working Institutional Routines**" see something like that working on almost any unit – rehab or on the other side unit. Get in, feeling really lousy, need to be taught the routines, then as you start to feel better you're learning the routines and incorporating them, trying to figure out how do I conform to them or navigate/negotiate or whatever so I can get out of here

07/21/2011 phone meeting with Dr. Lev. She could not understand the label - kept asking what I meant by "working". I have difficult time articulating. So I talked out what I have to date and we came up with: "**DEALING WITH THE ESTABLISHMENT/ORGANIZATION**".

07/22/2011 Last night was able to find in **two** places my hand notations referring to my past thinking about labeling this DEALING WITH or DEALING WITH THE ESTABLISHMENT. This is important because I don't want to use labels solely based on the suggestions of others. Using a "best fit" label - Glaser 1978 p 94 all along. Right now will stick with ESTABLISHMENT since it uses the words of the participant.

07/24/2011 Yesterday I worked with the cut memos/labels and sorted based on previous days' feedback from Dr. Lev and GT peer group. My biggest breakthrough was realizing that the CC - DEALING WITH - did not fit well as a phase in the process, because it has more explanatory power than I originally analyzed. The other progress I made was subsuming codes into more conceptual labels. This is what talking it out with the GT peer group helped - Core has to be in the narrative/descriptive of the theory

8-10/2011 The core category, DEALING WITH THE ESTABLISHMENT, emerged from the data. It addresses the main concern of hospitalized older adults with new-onset UI, which was "to walk" and get out - preferably "to go home". The core category emerged (Glaser, 1978; Glaser and Strauss, 1967; Holton, 2007) during the constant comparative analysis of field notes from the start of the study and through interviews of

Participants 01 to 06. The substantial code after in vivo coding was initially labeled “institutional routines” (see Memo XX - below) and subsequently emerged to “conforming to institutional care”. During a conference with Dr. Robinson, Co-chairperson (See XXXX), presentation and discussion about the concept of conformity lead to a “eureka moment” (Glaser, 1992, 2009b). The label “conforming” seemed too “surrender-like” and did not best capture what was happening in the data. Therefore, a revised label for the core category became “working it”. This process of discovering a “best fit” label was consistent with GT methodology. Glaser (1978) advised that a “best fit” label be assigned when the investigator identifies a “main theme”, which explains how the participants mainly try to solve their main concern, so that the investigator has a “...handle for thinking of them.” (p.94).

“Working it” did focus subsequent analysis of data and theoretical sampling and coding, which led to a refined label: WORKING INSTITUTIONAL ROUTINES. However, presentation and discussion of the core category and its theoretical relationships with other categories and properties with Co-Chairperson, Dr. Lev, (See XXXX 7/21/11) identified weak theoretical connections despite fairly dense conceptual descriptions of the category, and that the WORKING label did not conceptually transcend setting (Glaser, 1978, 1992, 2009b).

WORKING did not have strong “carry through”; meaning, it was not central enough to the other related categories; yet, it accounted for the large variation of the participants’ behavior, and reoccurred frequently, (Glaser, 1978; Glaser and Strauss, 1967; Holton, 2007). Moreover the label, WORKING INSTITUTIONAL ROUTINES, did not theoretically transcend setting, person, or time (Glaser, 1978, 1992, 2009b). Further analysis of the data and presentation to the peer GT group increased theoretical sensitivity.

DEALING WITH THE ESTABLISHMENT became the best label for the core category because it best explained how hospitalized older adults with new-onset UI went about resolving their main concern. DEALING WITH is central because, in comparison to the other categories, it relates “meaningfully and easily” to a larger number of categories and it reoccurs frequently (Glaser 1978). It has “clear and grabbing implication for formal theory”, because one realizes that any person in any establishment to some extent deals with that establishment (p. 98). DEALING WITH has “carry through” in that it helped the investigator to conceptualize the process of how the participants addressed their main concern.

09/30/2011 Meeting with Dr. Robinson who felt the label of the core was not neutral

10/2011 Dr. Lindgren replaced Dr. Robinson. Reviewed chapters to date.

11/21/2011 Dealing with Establishment/Situation is not saturated and not relatable to reader.

1-3/2012 Recruited and interviewed three additional participants.

- Desire for independence
- Automated – detailing how get used to toileting even when wobbly; proceduralized
- Being told/ being instructed
- Past experiences/knowledge – has history of UI that use as a reference – it was worse
- Don't want to bother workers
- Fighting it
- Determined (innate?)
- Difficult to explain – UI, not asking for help
- Life review- past hardships how d/w losses, current cause of hospitalization, reasons for dealing
- Degrees of informal support
- Looking for validation of what may be independently controlled
- Less **control** at night/sleeping
- Feelings frightful compared with other expressions of feelings about body changes
- UI new vs continues to happen – pain takes priority
- Various motivators to be a good patient – medical authority/expertise, pressure from loved ones, demonstrate competency
- Allowing staff to lead conversations
- Prior knowledge – from work (managerial type) and AA program – influence how interact with hospital workers
- Apologizing
- Medical authority
- Learning, reflecting – specific orders; need for modeling; need routines spelt out; self-defining, distinguishing, interpreting, surveying; seeking direction; searching for information; trying to make sense/interpret
- Causes of new-onset UI – drinking, sleeping pill
- Actions of informal caregivers; ama coercing
- Get out
- Degrees of recuperation
- Concealing – feelings, UI, etiquette
- Countering, rebelling, resistive, bucking
- Humor – reconnecting to staff, get out of trouble

- Hospitals are regimented
- Awareness of hospital liability

3/12/12 – **Getting well** enough to **get out** and go home – conforming-resisting continuum

6/4/12 - “What is it like for older adults to start having trouble with bladder **control** in the hospital?” but as the data was analyzed the categories and theoretical connections emerged (still emerging), it became a study not just about how they experienced new-onset UI – it is a study of how hospitalized older adults with new-onset UI experienced hospitalization – of which new-onset UI was one experience (a bodily change) among many.

6/5/12 - So what are these participants saying (behavior is focus!) – this is what I am keeping in mind as I reanalyze the data. They want to **feel secure** (safety) – that comes out emerges. Participants does not use those words – but some about **wobbling** and need for eye to improve so could **walk better – more secure/steady**.

- I don’t think that the conforming continuum is as strong – I see how it lacks saturation, but it is still a category – and saturated – but not to be a core category.
- d/w hospitalization or a better label is **getting out** - how the participants try to resolve their main concern. This is a theory of **getting out**. This gets explained by how they have to
- “Dealing with” is too broad. **Conforming** does not have enough saturation. Could it be “**getting out**” the majority of behaviors of participants have been about *getting out* of the hospital.
- Two sets of behaviors are used to get out - I need to think about these/analyze more. But this outline is a way to preliminarily organize my hard copy sort. They d/w situations, which is how they work towards *getting out*.
- First set: individual behaviors
- *learning* about the institutional context; comparing? minimizing UI; proving ability to get out; reminiscing?; regretting?
- Second set: Institutional behaviors; *Conforming* (even if not in best interest)
 - “*walk the line*”; *Trying to be nice (Use of humor apologizing)*; “*allowing of them*”; *Waiting*; *Calling for assistance*; *Passive vs active*
- *Advocating/negotiating* – is this a characteristic of active conforming?
 - *Resisting*
- Active (AMA incidents)? Vs passive (independently going to the bathroom – sometimes clandestinely?)

6/8/12 The timing of the interview provides insight into the stage of the hospitalization????

6/19/12 Conforming – a reciprocal nature to it? Resistive – when a line was crossed? Social norms

7/1/12 - Email to Dr. Lev and Lindgren:

My analysis of data shows how participants dealt with (d/w) body changes (new-onset UI because it was the focus of the study among other body changes). Reanalysis also shows how they d/w life changes (more so if body changes were not rehabilitating and discharge destination was not home or was questionable). There is a prioritization process; heavily influenced by their perception of hospital practices. Conforming is still emerging. I see resisting. I am seeing a pattern in how they conform/resist to body changes (addressing their individual context) - the interplay (with degree of conflict) between individual and institutional context heavily influences their behaviors. Behaviors focus on **following/conforming to hospital practices in order to "get out" of hospital**. Being in the hospital(the institutional context) suppresses the individual context - and, in turn, whatever is underlying. That 6/7 memo addressed **toeing the line** for only so long. As I continue to rewrite etc... analyzing this against other raw data/memo - try to apply to their private role/individual self reaches a limit - the one participant perhaps reached his limit of d/w his life changes (as he life reviewed) - he cries - but this is during the interview - not how he behaved before/after the interview when in his institutional self/role. The interview changed the context - temporary suspended hospital practices/context?

9/12 **Getting out - Stepping out** the hospital door. Dr. Lev does not see BSP

Behaviors may be “in vivo – perceivable by those persons involved” or purely heuristic (generally not perceivable by the persons involved, but demarcated by the sociologist for theoretical reasons) or some shade in between” ---- does my findings capture a bit of both – I can discuss in discussion how the study suspended the dual contextual conditions and provided me glimpse into the individual behavior hidden from hospital workers? Woooo – I do not mention “hidden” in findings – how do I address this, though – in passive conformity when participants – yes, with *concealing*. stages perceivable only after gone through; learned as go through??? Not sure about this because if they wish to forget – and do forget – as data suggests – findings are important to document because this will inform hospital workers to be aware and to care accordingly. I cannot alter the “basic substantive patterns of the process” – not all go through in the same manner – much variation. BUT the BSP can uncover which conditions or variables that theoretically account for the variation – in my findings this would be the influence of the dual contextual conditions, which are “infinitely variable”. Therefore **WALKING THE LINE to GET OUT** – can happen in other “units” settings (prison). Is it – durable and stable over time? Does it account for change over time? Can I take Walking Line process and apply to a new dual contextual framework – I say yes, both properties will be modified. For exam-

ple body changes are focus of patients, but for prisoners – this may be less concerning – still there. Prisoners will not have informal caregivers but will have degree of social support. They will try and foster humanistic connections with prison workers – to be better treated. I think mine has grab? Do folks read mine as hypothetical generalizations? Does mine have change built into it? I think it is open to new data – which will extend and further densify it – for now the solid initial structure of theory is there.

Hospital is a service organization – to provide care to very sick/dying – generally thought to be noble work – therefore, society view hospital workers as noble - good, righteous – caring literature has this undertone – but done in a place where no one wants to be. So by looking at the process of behavior – get out and away from the caring literature and look at how my participants viewed the care – or practices of hospital workers – a property of the process that participants followed – my findings are about behavior in response to care. Not what has been said about care – but about patient responses to that care.

Dr. Lindgren said it – we all conform – we all resist – then I pondered: all in what effort. I suggest it is in the effort to “walk the line” in order to accomplish an endpoint goal – then it becomes a balancing act between the individual context and the context of the structure supporting that goal. Therefore, in different dual contexts there may be different properties of each that still have yet to be discovered – and then prioritized as to which one influence the behavior toward the goal. For now, those categories and properties that immersed transcend setting, time, person.

Incident tripping – did this happen with my conforming to institutional routines??? Hmmm – spoke about it and others verified – except chairs – they did/did not – brainstormed – **working it** – not **working the system** (too negative); tried **dealing with the establishment** (in vivo words). **Conforming to ICR** was lacking explanations of other behaviors and was not tapping into the range of behavior or strategies used by patients. Conforming has possibility to land itself to negative connotations and risks speaking too much to social drivers/conditions rather than internal/individual strategies used by patients...

11/19/12 – Detailed outline shared with Drs. Lev and Lindgren: the pattern of exerting/**regaining control** teetered/fluctuated

11/28/12 - Balancing/teetering. Teetering = wobbling, unsteady insecure “to move unsteadily, uncertain, fluctuate”; Struggling to **name core that r/t losing/exerting/accepting**. Even if could wait errors on side of caution. Not familiar environment. Not confident need to be more certain. There is a gray area of feeling in **control** – somewhere in there the patient makes a decision to act or not act. *Teetering toward control regained.*

Awareness of teetering

Teetering about actions

Teetering “if” feeling of **control** – not a new category but implicit – teetering. Conforming/following – gives sense of **control**.

teeter totter - **control** teeters upward till down the other side - teetering - in vivo word "wobbly" - another used "unsteady" another - "it is dangerous - could fall" trying to race to BR independent - be sure not to "marry it" to one participant --- but the way that participant described "a feeling" - it can go either way when sick in hospital - that is the learning piece - to learn when appropriate exertion of **control** that fluctuates

Decision pathway is directed by HWs

Reviewed history of core categories:

Institutional routines > conforming to institutional routines> d/w establishment/institution/ working it (working what?)/ getting out/ walking the line

Substance similar ... name not grabbing?

12/3 Dr. Lev meeting: categories make sense. I spoke about the teetering through transitions – how sometimes there is **control** to appropriate exert and sometimes there is not – she agreed to using the word teeter. Moments of physical mastery that no longer need/want to submit – however these moments teeter. Want to go home but not well enough yet as per the BoHW who brought out AMA – inappropriate exertion of **control**. Verbally defended the concealing category – hides UI/feelings so can follow – a good patient "getting used to it" "resisting" "concealing" relate to the core - verbally defending this - each is an exertion of **control** - over body, space, time that contributes to **regained control** - balancing --- is teetering_--- until out of hospital --- even then continues if still recuperating.

wobbling **control**, wavering **control**

12/5/12 Walking their way out – teetering has more grab captures the wobble/uncertainty/teetering **control**

12/11/12

CONCERN: no longer regulate direct their body, time, space to do what they need/want to get through their day. LOSING **CONTROL** - deny and feelings (different from resisting - THIS is a strategy of exerting **control** - types: resist loss of body **control** (fight) and resist workers if perceive harm....

CORE: **Regaining control** (not sure about teetering in there - at some point it stops teetering - phase 3, not written yet - speaks to accepting control regained)

PHASES:

1) Transferring **control**: seeking controllers (friends/family/MD) or self-appointed proxy does the seeking, role transitioning, submitting to hospital care

2) Exerting Teetering Control - this is where I see the **control** teetering

Learning and Adjusting

3) next focus

12/14/12 Email to Dr. Lev and Lindgren

Since our meeting on 12/3 I have been working to address your written and verbal feedback as I follow your instruction to revise the Main Concern, Core Category and first two phases. I found the reference you suggested, Glaser (2002) in IJQM very helpful to me - think and write more conceptually. A brief update:

**I detailed the main concern to address your feedback of describing the evolution of the main concern.

I revised the section in the Appendices to address your feedback about Core Category - to provide samples of coding/memoing to show its emergence. In doing so, the label changed from **Balancing Control to Regaining Control - three properties: Transferring **Control**, Exerting **Control**, and Accepting/Coming to Terms with Degree of Regained **Control**/Remodeled Self

12/22/12: Exerting – incremental exertions of **control**

What do they DO to regain **control** – transfer **control**, exert **control** > exercising teetering **control** – exercise/practice – repeat actions to improve –learning (continuous and notion of past), following – negotiating (concealing – that helps both following and negotiating) resisting

NOTE: This Appendix was shared with Drs. Lev and Lindgren at 2/15/2013 meeting.

Appendix L: Full overview of the theory of Regaining Control

Main Concern: Loss of Control

Physical control - dependent upon biological capabilityⁱ; voluntary functions of the physical body necessary to manage routines of every day living.

Spatial-temporal control – management of the space around the physical body and the timing of physical actions.

Social control - management of one's behavior and interaction with other people

Core Category: Regaining Control – a three phase process:

Phase	Transferring Control	Exercising “Wobbly” Control	Adjusting to Degree of Control Re-gained
Definition	Active or passive handing over of control to provisional controllers	Unsteady progressive and iterative exertions of control that fluctuate and may, or may not regain control with each effort.	Acclimating to the extent of control regained
Timing/ Onset	Prehospitalization New or recurrent loss of biological capability due to biological damage ⁱⁱ	Begins with biological recuperation	Begins when biological recuperation plateaus
Properties	Consulting Submitting	Learning Following orders Directing Provisional Controllers Resisting Concealing	Reminiscing Reassigning control Leaving the institutionalized patient behind

Conditions:

Biological Recuperation - an involuntary and not completely predictable return of biological capability

Recuperation Plateau – involuntary return of biological capability that has not fully returned to a pre-hospitalization level, but, as determined by hospital workers, has reached a level of physical control regained that no longer requires hospital care.

Understandings of Hospitals - patient perspectives about hospitals shaped from prior hospitalizations or experiences with hospitals.

Provisional Controllers – individuals who protect, restore, and supplement degrees and aspects of loss of control for the participant

- Formal – paid health care workers, such as hospital workers
- Informal – trusted individuals, such as spouses, children, friends

ⁱ Biological Capability – the body's capacity to intentionally control the body

ⁱⁱ Biological Damage – illness or injury to the body that decreases its biological capability

Curriculum Vitae

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Education

1986	St. Joseph Hill Academy, Staten Island, NY
1989	AAS, College of Staten Island, City University of New York
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Employment

1991-1997	Staff Nurse, New York University Medical Center, New York, NY
1996-2000	Gerontological Nurse Practitioner, The Brooklyn Hospital Center, Brooklyn, NY
1997-1998	Gerontological Nurse Practitioner, Regan and McGinn, Staten Island, NY
1998-1999	Gerontological Nurse Practitioner, Bayley Seton Hospital, Staten Island, NY
1998-2011	Clinical Associate Professor, College of Nursing, New York University
2006-2008	Adjunct Faculty, College of Staten Island, CUNY
2008-Present	Assistant Professor, The Evelyn L. Spiro School of Nursing, Wagner College, Staten Island, NY

Publications

- Dowling-Castronovo, A. (2009). Man with urinary incontinence after prostate surgery. In M. Lunney (Ed.), *Critical thinking to achieve positive health outcomes: Nursing case studies and analyses*. Hoboken, NJ: Wiley-Blackwell.
- Dowling-Castronovo, A., & Specht, J. (2009). Assessment of transient urinary incontinence in older adults. *American Journal of Nursing*, 109, 62-71.
- Dowling-Castronovo, A. (2011). Why is my mother wearing a diaper? In M. Wallace-Kazer & L. Neal-Boylan (eds). *Case Studies for Gerontological Nursing for the Advanced Practice Nurse*. Des Moines, IA: Wiley-Blackwell & Sons Publishing.
- Dowling-Castronovo, A. & Bradway, C. (2012). Urinary incontinence. In Boltz, M., Capezuti, E., Fulmer, T. & Zwicker, D. (Eds.). *Evidence Based Geriatric Nursing Protocols for Best Practice* (3rd ed) (Chapter 18, pp. 363-387). New York: Springer Publishing Co.
- Dowling-Castronovo, A. (2013) Try this: Best practices in nursing care to older adults. Urinary incontinence assessment in older adults: Part II – transient urinary incontinence. In M. Boltz (Ed.) Try This: Best Practices in Nursing Care to Older Adults from the John A. Hartford Foundation Institute for Geriatric Nursing, Issue 11.2. Available at http://consultgerirn.org/uploads/File/trythis/try_this_11_1.pdf