Theory of Regaining Control: How Older Adults with New-Onset Urinary Incontinence Address Loss of Control

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Abstract

Older adults viewed new episodes of urinary incontinence as a part of a much broader concern during hospitalization: loss of control with physical, spatial-temporal, and social aspects. During hospitalization, a time crisis, patterns of regaining control became evident: transferring control, exercising "wobbly" control, and adjusting to degree of control regained. Three conditions modify this process of regaining control. Findings offer a unique perspective about the relationship of control and patient-centered care that provide a basis for research aimed to improve hospital care for older adults who are likely to experience new-onset urinary incontinence.

Keywords: control, grounded theory, incontinence, new-onset urinary incontinence, older adults, patient-centered care, urinary incontinence.

Introduction

Urinary incontinence (UI) is an involuntary loss of urine sufficient to be characterized as a problem (Fantl, Newman, Colling, 1996; Resnick & Ouslander, 1990) affecting approximately 26 million Americans (National Institutes of Health: NIH, 2008). There are two categories of UI: transient, or acute UI, and chronic or established UI (Fantl et al., 1996). The term new-onset UI, which is classified as acute, was first noted in the literature to describe the finding that 12% older adults, who were continent at time of admission, developed UI during hospitalization (Sier, Ouslander, Orzeck, 1987). Since that time, evidence-based clinical guidelines that guide assessment and treatment of UI (Fantl et al., 1996) have been developed and tested. Nevertheless, these guidelines were developed with evidence from studies that focused on individuals in long-term care settings (LTC), such as

nursing homes and residential facilities, or the community. The literature about UI offers little about new-onset UI among older adults in the hospital setting.

In the literature, new-onset UI is portrayed as what Glaser (1998) has termed a professional problem. What individuals with new-onset UI view as problematic and how they go about addressing the problem has not yet been discovered. Instead it has been studied more from what professionals perceive as problematic. Incidence reports of new-onset UI among hospitalized older adults range from 12% to 36% (Palmer, Myers, & Fedenko, 1997; Palmer, Baumgarten, Langenberg, & Carson, 2002; Sier et al., 1987; Kresevic, 1997; Zisberg et al., 2011). Depression, malnutrition, and dependency are risk factors (Kresevic, 1997). Male gender and cognitive impairment are significantly associated with new-onset UI patients after hip surgery; and, specific to women with hip fractures, hospital-acquired UI is significantly associated with admission from LTC facilities, confusion, and mobility impairment (Palmer et al., 1997; Palmer et al., 2002). The use of indwelling urinary catheters, adult diapers, and dependency are significantly associated with new-onset UI (Zisberg et al., 2011).

New-onset UI has been essentially studied from the perspectives of medical and nursing staff and not clearly delineated from established UI (Connor & Kooker, 1996; Cooper & Watt, 2003; Dingwall & Mclafferty, 2006; Fonda & Nickless, 1987; Hancock, Bender, Dayhoff & Nyhuis, 1996). It has been documented that hospitalized older adults (n=117) differed in their preferred treatments for UI in comparison to hospital staff (Pfister, Johnson, Jenetzky, Hauer, & Oster, 2007). Nevertheless, the preferences and perspectives of older adults with new-onset UI have not been documented. Since there were no identified studies from this perspective, the purpose of this study was to examine the experience of new-onset UI from the perspective of hospitalized older adults.

Method

Grounded theory (GT) methodology (Glaser, 1978, 1992, 1998, 2002; Glaser & Strauss, 1967) was used to discover the main concern of older adults with new-onset UI and document how they work to resolve that concern. Institutional Review Board approvals from both the University and Hospital, a 714-bed teaching hospital in a northeastern urban area of the United States, were obtained. I educated the hospital staff about the study and the need for their assistance to assist in the recruitment. Two Nurse Practitioners (NPs) became unit-based "champions" who identified patients that met three of the inclusion criteria: 1) age, 2) cognitively intact, and 3) ability to speak English. If a patient met these criteria, then the NP obtained their permission to introduce me. I then introduced myself, the study, consent, and evaluated for the other inclusion criteria: 1) agreement to participate, 2) continent six months prior to hospitalization, and 3) experience of at least one episode of UI during hospitalization as reported by patient and/or hospital staff. Exclusion criterion was that the patient did not have an indwelling urinary catheter at the time of recruitment. I

collected and analyzed over 4,230 lines of data from: 61 field visits totaling almost 170 hours to the inpatient rehabilitation unit, interviews with 14 (11 recorded and transcribed) older adult patients, and their medical records.

Field visits took place from 8:30AM to 5PM. During that time the majority of patient and unit activity occurred. Approximately 25 hours from 5PM to 8PM and from 5AM to 8:30 AM were also included to gain the broadest perspective of the milieu. During field visits, I participated in unit rounds with the interdisciplinary team, attended ad hoc staff in-services, meetings, and observed physical therapy sessions. Interviews ranged from 35 minutes to 75 minutes and were scheduled according to patient preference and not during physical therapy hours. Two interviews were done after discharge from the hospital: one in a participant's home and the other in a long-term care facility. To minimize the risk of disclosing participants' identity, each participant was assigned a code that was used on all documents. In analyzing how these individuals dealt with their main concern, loss of control, the theory of *regaining control* emerged. Participants were concerned with broader aspects of control, not just the loss of bladder control. Before, during, and after hospitalization, they are concerned with three aspects of loss of control: physical, spatial-temporal, and social. This loss of control is triggered by illness or injury, such as a stroke, that damages biological capability. Dependent upon the extent of this biological damage, there is a gradual or abrupt loss of the biological capability to physically control the body to perform routines of everyday living. Spatial-temporal control refers to how individuals manage the space around them and the timing of their actions. Social control is how they behave and interact with people. Incidences from this data set of the substantive area [noted in italics] and a post-hoc literature review illustrate how this action-focused theory 'processes out' (Glaser, 1998) during a period of crisis, which for this population was hospitalization. Ultimately individuals want to get out of the hospital and regain as much control back as possible: *get out of here. Be independent – able to do for myself.*

Theory of Regaining Control

The theory of regaining control is an iterative and overlapping three-phase intrapersonal and interpersonal process addressing how participants constantly work to regain control. Transferring control is the first phase that begins before hospitalization when participants act on their loss of control by consulting informal and formal sources and then submitting to the care provided by hospital workers. When biological recuperation begins, and continues, participants practice exercising "wobbly" control. During this second phase, they initially follow orders from hospital workers. As they progress they exhibit behaviors of directing provisional controllers, resisting, and concealing. When biological recuperation plateaus, participants begin adjusting to degree of control regained. During this third 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. In addition

to biological recuperation, other influencing conditions are participants' understandings of hospitals and informal and formal caregivers, referred to as provisional controllers.

Transferring Control

Initial reactions to loss of control are characterized by denial, refusal, doubt, or inability to recognize that hospitalization may be necessary.

> When this [stroke] happened . . . I did not listen to my girlfriend . . . 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.

When biological damage results in loss of control, transferring control becomes evident. Transferring is done to maintain as much of the remaining aspects and degrees of control as possible and initiate treatment for biological damage. To varied degrees, participants transfer varied aspects of control to others, such as family members and hospital workers. These family members, or friends, become informal provisional controllers who protect, restore, and supplement degrees and aspects of loss of control for the participant. When the need for supplemental control is greater than what these informal provisional controllers can provide, formal sources are needed. When hospitalization is needed, formal provisional controllers, such as hospital workers, supplement loss of control primarily by targeting the biological etiology. Participants with their informal provisional controllers enter hospitalization with varied understandings of hospitals; these perspectives about hospitals were gained from prior experiences with hospitals. A continuum of active to passive transferring depends upon the degree of biological injury.

When biological damage is not too debilitating, participants are able to direct how aspects of control will be managed. Active transferring was the case for one participant, who was the caregiver for her ill husband. She temporarily transferred usual daily caregiving tasks to her daughter to perform during her planned hospitalization. When biological damage is more debilitating, control is passively transferred. This means that participants rely on others to lead efforts to regain control or, simply, take control. Such was the case for one participant, who suffered extensive physical loss of control due to a stroke, which required his wife to initiate emergency services. Transferring control has two properties: consulting and submitting.

Consulting

Consulting is actively seeking or passively receiving needed advice. Advice comes from informal sources, such as family or friends, or from formal sources, such as health care professionals. These people to varying degrees become the participant's provisional controllers.

> I feel funny . . . head is numb—whole ground is a whirlpool and the walls are going around. I was like paralyzed . . . couldn't manage . . . went to the bathroom and did what I had to do. Then . . . called my daughter, "'. . . I am calling up the ambulance, don't feel good at all.' [EMTs] came . . . checked me over, '. . . have to take you to the hospital.'

When denial, refusal, doubt continue or participants are unable to recognize that loss of physical control needs hospitalization, there is a need for provisional controllers to recognize and act as a proxy:

> 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.'

This timeline from the trigger to hospitalization depends upon the degree of biological damage and its affect on loss of control. Those with unplanned hospital admissions experience abrupt losses that necessitate emergency hospitalization. Others plan their hospital admissions to address incremental and cumulative losses that eventually require professional intervention.

Submitting

Submitting is yielding to the authority of hospital workers. Individuals 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 . . .Just cleaned me up.

Individuals relinquish degrees and aspects of control, consistent with the extent of biological damage and physical losses of control. This relinquishment ranges from minor aspects and amounts of control 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:

> 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.

Individuals depend on hospital workers to facilitate biological recuperation and assist them to navigate hospital space, time schedules, and social surroundings. The two properties, consulting and submitting, are most notable during this transitional period from daily living to hospitalization. However, they may reoccur in response to recurrent or new losses of physical control.

Transferring control is initiated to limit the participant's biological damage through treatment for a period of time until biological recuperation begins and individuals work to regain control. Dependent upon degree of biological recuperation this transferred control may or may not be fully regained. With recognition of biological recuperation and returning capability to physically control some actions, the need to submit lessens. This pivotal point begins the second phase of regaining control.

Exercising "Wobbly" Control

This phase comprises iterative exertions of fluctuating control. Individuals may recognize feelings of biological recuperation that they may exercise physical control but, at the same time, have feelings that this physical control waxes and wanes. They practice exercising the three aspects of control—physical, spatial-temporal, and social—by trial-and-error to regain gradually more and more control. These efforts may, or may not, result in partial or full recovery of control. Five properties depend upon current conditions especially the state of biological recuperation: learning, following orders, directing provisional controllers, resisting, and concealing. Cyclically, learning is interdependent and strongly linked with the other four properties as individuals repeatedly learn and act—then learn and act, again and again. They may enact any or all of the other four properties that manifest both in isolation and in numerous combinations.

Learning

Individuals sort current experiences through their understandings of hospitals as they learn how biological recuperation and provisional controllers influence their exercising "wobbly" control. By repeatedly observing, interacting, interpreting, and reflecting on actions taken (both their own and those of provisional controllers), they learn from intrapersonal and interpersonal cues. Individuals observe intrapersonal cues of biological recuperation and learn how it signals a returning capability to physically control:

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

As individuals attend to intrapersonal cues of biological recuperation they observe verbal and non-verbal interpersonal cues during interactions with provisional controllers. They look for interpersonal cues that they are ready; these provisional controllers will allow or support them, to regain control. Individuals interpret and reflect upon combinations of intrapersonal and interpersonal cues to determine how to practice exercising "wobbly" 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 . . . 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.'

Individuals also learn about exercising "wobbly" control from 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. In contrast, an unsuccessful outcome, such as a fall, occurs when exertion of wobbly control is either not consistent with the level of biological recuperation or an unfortunate outcome of chance. This results in a relapse to the earlier and more dependent phase of transferring control. Individuals learn that outcomes fluctuate and are unpredictable. Exercising "wobbly" control does not always follow a progressive pattern:

> And it [urine] poured all over the floor. I had to change all my clothes. It's an accident . . . 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…

Despite an uncertain probability of outcomes when independently exercising "wobbly" control, successful outcomes likely reinforce exercising independent actions. Furthermore, individuals with strong feelings of biological recuperation and desire to exercise control broadly interpret, or misinterpret, ambiguous interactions with and among hospital workers, which many increase the risk of an unsuccessful outcome, such as a fall. Such was the case when a participant misinterpreted what he heard among therapists about his independently walking in his room. Subsequently, he successfully exercised wobbly control a few times: "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, explicit directions, orders, during interactions with hospital workers result in a greater chance that individuals experience positive outcomes. A participant explained his choice to spend a good amount of time sitting in a chair, because of clear directions, "Don't lie in bed much. Sit in the chair all the time."

After exercising "wobbly" control, individuals interpret and re-interpret how to re-exert by reflecting on actual and potential outcomes. After a transporter informed a participant about attending a group therapy session, the participant quickly interpreted that others would be in their night clothing for a yoga session. As a result, she remained in her hospital gown because there was minimal risk of losing social control. Other reflections, such as learning the pattern of activity on a unit, requires longer periods of time.

When learning, individuals introspectively and repeatedly observe, interact, interpret, and reflect upon intrapersonal and interpersonal cues, to determine how to enact the other four properties: following orders, directing provisional controllers, resisting or concealing.

Following orders

Following orders is carrying out care routines prescribed and enacted by provisional controllers, particularly hospital workers. Following orders successfully exercises "wobbly" control to achieve milestones that prove to provisional controllers and themselves that biological recuperation and regaining control are occurring to the extent needed to go home. When following orders patients fulfill their responsibility of the social role—being a patient. Prominent behaviors are calling or waiting for assistance from hospital workers. One participant bluntly shared this perspective about needing supplemental control from the nursing staff 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'." By following orders individuals exercise

> "wobbly" control in a way that gets them closer to getting out of the hospital: Each step in the gym is a step closer to the door out of here.

Following orders eases the transition through exercising "wobbly" control with learning experiences that reinforce successful exertions of "wobbly" control because hospital workers physically assist and/or direct their navigation of space and time until they are physically able to independently regain spatial-temporal control:

> So if you weren't able to use the walker, [Nurses] 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.

Following orders is a responsibility of being a patient. Patients are responsible to themselves and their provisional controllers to facilitate their biological recuperation and return as much as possible to pre-hospital living. Patients must come to terms with their reliance on hospital workers and responsibilities, such as *have[ing] to go to therapy*. This was evident during times that participants tried to avoid therapy. In response, hospital workers reminded them of their responsibility to participate in the plan of care, specifically therapy. After these persuasions, participants with sufficient biological recuperation attended therapy.

Common behaviors of following orders are following the rule to call for or wait for assistance. Doing so avoids reprimand by hospital workers, *they yell at you;* or unsuccessful outcomes, such as a fall. Either of these consequences jeopardizes any control regained. Individuals avoid increasing risk of losing any or all aspects of control when following this rule.

Directing provisional controllers

When individuals experience control regained from biological recuperation, learning, and following orders, they exercise wobbly control in a social way by directing provisional controllers. They modify the behaviors of their provisional controllers to acquire more effective and empathetic supplemental control. Behaviors include: developing individual connections with hospital workers, asserting, negotiating, and training.

Directing is done by developing and fostering individual connections among a variety of institutionally created relationships with hospital workers. They may call hospital workers by name or an endearing nickname, give flattering remarks, joke, entertain, and/or apologize. All to receive reciprocal treatment:

> You're not giving them command. Treat them as a patient carer [sic]. . . 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. . . appreciation, kind words . . . . Then they come willingly to help you quicker.

Asserting, or speaking up, for themselves is done to direct.

> I bitched, 'No, no, no loves, stop chatting, let's move it!' [laughing] . . . stop your chit chatting about someone around the corner. I need to go to the bathroom.'

Negotiating is another behavior of directing. Over the course of a few days, a participant negotiated with nursing staff by repeatedly demonstrating to them that he would not walk alone in order to sit on the toilet alone to exercise control of a *shy bladder.* Directing occurs when training provisional controllers:

> She [night-shift nursing assistant] has never looked after me in the morning. Train the nighttime carers. Their routine is different from morning carers . . . brushing teeth for example—take me to 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, it is vital that provisional controllers to be willing and able to respond. Realistically, re-directing is necessary, because participants experience different reactions from different hospital workers: W*ell, each shift has different people reacting differently. Some will react fast, and some really wouldn't give a damn.* When exercising "wobbly" control with multiple hospital workers learn to behave differently with different hospital workers.

Resisting

Resisting is defending against perceived threats to regaining control, especially to control regained. Resisting protects degrees and aspects of control that individuals have regained. There are intrapersonal and interpersonal ways of resisting that are distinctly different from the denial, refusal, doubt, or inability to recognize a loss of physical control that begins the process of regaining control.

Intrapersonal resisting occurs when individuals press on, or push themselves, to exercise, such as working through difficult therapy sessions. This property of exercising "wobbly" control occurs in when individuals have regained more of their physical control during biological recuperation. Physical control is then strengthened. Individuals struggle to regain physical control that, although still fluctuating, has become to some extent steady since the start of biological recuperation.

Interpersonal resisting is evident when individuals verbally or physically refuse to follow orders or assistance from provisional controllers. Individuals resist following orders if they perceive that actions of hospital workers jeopardize control regained, especially physical aspects, or may cause another loss of control or biological damage: [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.

Concealing

Concealing is masking signs and symptoms of aspects and degrees of loss of control. This is a unique behavioral characteristic simultaneously enacted during following orders, directing provisional controllers, and resisting. Dependent upon its type and degree, physical loss of control may be more difficult to conceal in comparison to the spatial-temporal and social

aspects. For example, new-onset UI is more concealable than a stroke's persistent paralysis of the body and inability to speak.

Participants experience changes to their biological signal to void: they *just leaked.* Concealing by wearing adult diapers contains the physical and temporal loss of urine. This promotes following orders. A feeling of, and exercise of, stronger physical control resulted:

> 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.

Concealing is evident when participants hide negative feelings and practice "being nice". Different from developing connections, this type of concealing masks expressions of negative feelings when following orders.

> Not liking them [some hospital workers] . . . I want them [hospital workers] to say, 'He was very, very good—oh, he was a terrific patient. He did everything we asked.' . . . I don't curse, yell, scream. Um, conversation—good dialogue. I try. I talk with them, not above them.

Or, when directing workers:

> 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...

Concealing occurs when they want to be viewed as having control:

> 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.

During exercising "wobbly" control, individuals learn how three conditions—biological recuperation, understandings of hospitals, and provisional controllers—influence following orders, directing provisional controllers, resisting, and learning. Regaining physical control supersedes feelings and desires for spatial-temporal and social aspects of control. When biological recuperation plateaus and cannot benefit more from hospitalization, individuals transition to the last phase, adjusting to degree of control regained.

Adjusting to Degree of Control Regained

Hospital workers decide when an individual no longer requires hospitalization based upon a biological recuperation plateau. Although a level of physical control is regained that no longer requires hospital care, this does not necessarily equate to a full return of biological capability consistent with pre-hospitalization level. There are three properties: reminiscing, reassigning control, and leaving the institutionalized patient behind.

Reminiscing

Reminiscing is reviewing past losses experienced in life and comparing them to current aspects and degrees of loss of control. Participants review salient moments of their lives when they endured losses and draw upon positive attributes searching for innate strength.

Remote past events and recent past events are reviewed. Data points provided glimpses of how lessons and skills from those past experiences help work through regaining control. For example, a participant attributed his ability to direct provisional controllers to past experiences:

> I managed [sports] teams in AA [Alcoholic Anonymous]. 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.

Individuals reminisce about the recent past events causing hospitalization comparing to current degrees of loss of control to the losses that occurred at the onset. They distinguish that those losses during the initial period were more life threatening or impeding than present impairments. These initial losses become a comparison marker that fosters coming to terms with and adjusting to current degrees of physical control regained:

> 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.

During reminiscing, individuals focus on the role of informal provisional controllers:

> If it weren't for [daughter] I would have been gone a long time ago. . . . 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.

These informal provisional controllers influence the process of regaining control, and at this point these controllers may facilitate the transition out of the hospital.

Reassigning control

Reassigning is an active or passive shifting of current supplemental control among provisional controllers. This may include shifting control to health care workers in other health care institutions, such as nursing homes. Similar to the continuum of active to passive nature that that initiates this process of regaining control, the degree of biological recuperation strongly influences how individuals reassign control.

With a greater degree of biological recuperation and regained control, participants are able to reassign control in an active manner and be primary controllers. They have regained enough control to demonstrate to themselves, and to provisional controllers, the capability to safely manage at home. These individuals actively reassign residual losses of control, mostly spatial-temporal and social aspects that have been managed by formal provisional controllers to new formal and/or informal provisional controllers. These controllers facilitate the transition out of the hospital by supplementing residual degrees and aspects of loss of physical control to manage daily routines. Incidences in field notes illustrate participants making arrangements with family members to carry out tasks, such as food shopping.

With substantial residual losses of physical control, participants passively reassign control. Although, these individuals may show degrees of shared controlling, they mostly reassign control in a passive manner to informal provisional controllers who become the primary controllers. Together, they must demonstrate to hospital workers the ability to

manage living safely at home. For example, a participant was *the last to know* about a discharge planning meeting scheduled to plan a *furlough* (visit home). During this furlough he and his girlfriend needed to physically demonstrate safe management in the home environment.

When participants are unable to demonstrate sufficient control regained, and do not have informal provisional controllers to safely provide supplement control, the provisional controller best positioned to be the primary controller plans discharge to a long-term care (LTC) facility. This controller actively reassigns supplemental control to other formal or informal provisional controllers as needed. Field notes illustrate how a participant disabled from a stroke was discharged to a nursing home (one type of LTC facility) for additional therapy. This was intended to be temporary while the spouse worked to prepare their home to spatially accommodate the participant's residual loss of physical control after a stroke.

After hospitalization, individuals continue working and reworking through the process of regaining control dependent upon degrees and aspects of reassigned control and biological capabilities. Individuals who shift control to staff in LTC facilities face the possibility of permanent institutionalization. When discussing this possibility one participant shared, *I'm 85. How many can say they've lived to this age?* Having experienced multiple and more severe setbacks during hospitalizations different from other participants, this participant shifted control to a 'higher power' and viewed: *suffering is part of God's plan.* Those who require continued institutionalized care, such as in a LTC facility, may not progress to the next, and final, property.

Leaving the institutionalized-patient behind

In addition to physically leaving the hospital, this property includes forgetting unpleasant experiences during hospitalization. Individuals do this in order to focus on returning to daily living. This was evident when eligible patients refused to participate in the study because they wanted to forget the experience of new-onset UI. Forgetting unpleasant experiences has an undefined ending, which may occur well-after discharge, or may never completely occur. Loss of control elicits strong feelings of concern, as words used by participants illustrate: apprehensive, embarrassment, anger, horrible, and frustration, which may be difficult to forget. 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. After hospitalization, purposeful and wishful forgetting may continue *to forget* the *nightmare* of a health crisis.

Purposeful forgetting is different from illness-induced forgetting that occurs when participants are at their sickest during hospitalization. They may simply be unable to recall some events even when intentionally making an effort. Illustrating this was a detailed-oriented participant, who tried, but failed, to recount the hours after surgery: …what happened from when I came up from surgery [pause] I guess I don't even remember what happened.

Individuals approach the end of regaining control when 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 reengage 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:

> Now when my kids come by, and ask me how am . . . I doing? I tell them I'm okay . . . 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 wedding this year, a wedding next year.

Discussion

The control literature suggests that relinquishment of control is a choice 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 based on perceptions of internal-external control of reinforcement (Bandura, 1997; Miller, 1980; Reid, 1984; Rotter, 1966; Skinner 1996). In contrast, findings from this study illustrate that this is not always a choice when dealing with loss of physical control triggered by biological damage. In this study, the findings for transferring control support the normalizing of symptoms (Glaser, 1975) done to maintain usual patterns of internal-external control (Rotter, 1966).

Similarly there are other instances in the literature. Individuals suffering heart attacks initially "normalized their symptoms" (Johnson & Morse, 1990, p. 128) to maintain the status quo until too difficult to continue, or family and friends intervened, and sought hospital care. Other hospitalized older adults relinquished control as they processed from their "usual way of being" to "identifying" and "confirming" their health problem with health professionals and then "transitioned" through hospitalizations (Jacelon, 2004a, p. 223-554). Submitting corresponds with instances in the literature in which hospitalized older adults relinquished control to "rely on authority of hospital staff'" (Jacelon, 2004b, p. 32) for hospital care and when others "passively allow[ed] themselves to be cared for by others" (Johnson & Morse, 1990, p. 129) after a heart attack. Biological recuperation was also noted among men after prostatectomy (Petry, et al., 2004) and during post-operative recovery periods (Allvin, Berg, Idvall, & Nilsson, 2007). Findings from this study contribute to this body of control literature by illustrating the complexity of relinquishment of control posited by Miller (1980) in nuanced behavioral patterns not found elsewhere.

The theory of regaining control provides a basis for research aimed to improve hospital care for older adults who are likely to experience new-onset UI. Equally important is the theoretical relevance to other situations where loss of control requires degrees of transferring of control. Supporting this assertion are incidents in the literature that illustrate how parts of this theory exist among other groups. Specifically, the main concern of loss of control and its three aspects are found as unexplored anecdotal references in the theoretical literature about control (Bandura, 1997; Heckhausen & Shultz, 1995; Miller et al., 1989; Reid, 1984; Skinner, 1996) and among studies of hospitalized older adults (Boltz, Capezuti,

Shabbat, & Hall, 2010), patients in intensive care units (Hupcey, 2000), patients after myocardial infarction (Johnson & Morse, 1990), people living with implanted cardiac defibrillators (Dickerson, 2002;Morken et al., 2009), amputees interactions with hospital workers (Sjödahl, Gard, & Gun-Britt., 2008), and patients with cancer making decisions about complementary therapies (Truant & Bottorff, 1999). In comparison to these findings in the literature, regaining control describes and explains a much richer and nuanced view of how embodied control is embodied after suffering its loss, making findings likely to be useful to those involved with other populations of hospitalized adults.

Although hospitalization is needed to address the biological damage causing loss of control, it further contributes to two aspects of loss of control: spatial-temporal and social. This seems closely related to how Taylor (1972, p. 159) described hospital workers' inability to provide personalized care, which influenced how people forfeited control to hospital staff. Others have also suggested that the institutionalized nature of hospital settings depersonalizes clinical encounters (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993; Larsen et al., 2013). No longer in familiar spaces of daily life, individuals must stay in this complex controlled setting designed to service many patients. Individuals lose spatial-temporal control when they are told where and when to sleep, to eat, go to therapy, and diagnostic testing. Similarly, Hupcey (2000) noted that hospitalized patients exhibited intense feelings of loss of control including an inability to self care (physical control) and confinement to bed (spatial control). As hospital patients, individuals temporarily live and interact among people not of their choosing—other patients and hospital workers. Organizational attributes of hospitals must be regimented, but, as a result, impede individual patient freedom, in order to service many patients and constituents (Allshouse, 1993; Taylor, 1972). In addition, current findings support the general patient belief that it is difficult to modify the organization of the hospital (Penney & Wellard, 2007).

Regaining control offers a unique perspective about the relationship of control and patient-centered care, which explains what it means for the patient to be 'the source of control':

> 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. (Institute of Medicine, 2001; p. 61)

Literature supports the theory of regaining control. Patients are not interested in shared-decision making when they are acutely sick (Institute of Medicine, 2001). People expect to lose a sense of control and autonomy in the hospital (Allshouse, 1993; Mangset, Tor Erling, Førde, & Wyller, 2008) and to do as told by hospital workers (Mangset et al., 2008; Olofsson et al., 2005; Waterworth & Luker, 1990). Although, patients want hospital workers to lead these efforts while respecting individual differences (Sjödahl et al., 2008). Arguably, patients not only want, but also need, formal provisional controllers to lead or provide opportunities for developing connections.

Published frameworks exhibit the challenges for studying, enhancing, and routinizing shared-decision making (Bernabeo & Holmboe, 2013; Towle & Godolphin, 1999). Hospital organizations have yet to create systematically a social norm to foster participatory control

among patients, family, and workers. This is a shortfall, especially since current findings about learning are similar to observational learning by which people learn how to exercise control by observing others (Bandura, 1997). Furthermore, while current trends place the needs of the patient first (Berwick, 2009), it is unclear who is responsible for defining "needs" particularly during a health crisis that necessitates hospitalization and individuals have unstable biological damage and "wobbly" control.

Although, current findings suggest that individuals and their informal provisional controllers are most dependent upon the expertise of formal provisional controllers to take control and direct care during hospitalization. Similar incidents in the extant literature support the need for sound authoritative orders (Boltz et al., 2010; Penney & Wellard, 2007; Sjödahl et al., 2008; Torheim & Gjengedal, 2009; Waterworth & Luker, 1990). 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). All of which suggest that during times of crisis individuals need powerful, or more abled others, to control what they, themselves, are unable to control.

Regaining control suggests a pattern of patient behaviors that has important implications for organizational efforts focused on patient-centered care (Gereteis et al., 1993; Institute for Family-and Patient-Centered Care, 2013). Others have found that patients may be reluctant to participate in hospital care (Boltz et al., 2010; Waterworth & Luker, 1990) adding further support to the need for formal provisional controllers to lead shared-decision making, especially during the more acute phase of transferring control. Rather than "freely" giving 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. Yet, regaining control also illustrates patients' natural tendencies for shared-decision making that need to be recognized and fostered by hospital workers. Although, it is evident that health care providers must lead, teach, or coach (Frampton et al., 2008), patients to become sources of control, future study is needed to gain a better understanding of how the three conditions—biological recuperations, understandings of hospitals, and provisional controllers—modify regaining control during exercising "wobby" control and leaving the institutionalized patient behind phases.

Specific to the professional problem (Glaser, 1998) of new-onset UI among hospitalized older adults, the individual bladder needs of patients are not being addressed (Clark & Rugg, 2005; Connor & Kooker, 1996; Dingwall & Mclafferty, 2006; Nikoletti et al., 2004). In support, participants in this current study thought toileting activities bothered hospital staff. It seems clear that hospital nurses and therapists need to lead, teach, and coach patients and their family members about strategies to promote bladder control (Dowling-Castronovo & Bradway, in press).

Limitations of this study included the setting, challenges with privacy and scheduling, and pre-defined study materials. The inpatient rehabilitation unit was selected to maximize recruitment efforts. These patients were considered to be less frail than those on other acute care units. Data drawn from other substantive areas might be different or provide greater variation. For example, data from other inpatient units or the emergency

department may identify incidents where new-onset is more nascent, isolated, or transitory. However for this current study, hospital-based organizational constraints limited access to these other units. Semi-private patient rooms, a common practice among most hospital units, limited the ability to conduct private screening and interviews. Therapy schedules, although vital to patient recovery, affected timing of interviews. For example, three participants chose post-hospitalization interviews. This resulted in retrospective data that did not capture the real-time reality of hospitalization. Nevertheless, different real-time data informed how participants were adjusting to the degree of control regained after hospitalization. Pre-defined study related materials identified and focused on new-onset UI, a professional nursing problem. This focus might have caused two groups of eligible patients to reject participation: patients who did not view new-onset UI as worthwhile or had other pressing concerns; and patients who shared vivid details of their new-onset UI during screening, but declined formal consented participation in the study because they did not want to revisit or detail their experience again. This unavailable data may, or may not, have influenced the discovery of the theoretical findings. While these limitations may delimit the application of regaining control to older adults with new-onset UI, future researchers can readily apply the knowledge gained from the theory of regaining control and modify it based on new data. Future research may focus on other populations, such as overall patients experiencing hospitalization.

Conclusion

This current study detailed three important perspectives of control not identified elsewhere: 1) the action-oriented nature of control that patients identify as important, 2) the process of control sharing between patients and provisional controllers, and, 3) the periods of acute and transitory changes in control that occur throughout a period of illness or injury that requires hospitalization. Regaining control is a complex overlapping three-phase process that explains how individuals respond to a broad nuanced loss of control. Three conditions emerged as modifiers that further explain how individuals work through the process of regaining control.

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