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Hospital to Home: Family Caregiver Perspectives of Discharge Transitions of Seniors with Dementia

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Hospital to Home: Family Caregiver Perspectives of Discharge Transitions of Seniors with Dementia

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Dedication

This dissertation is dedicated to the family caregivers who generously shared their time and expertise. The stories of their experiences made this work possible.

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Hospital to Home: Family Caregiver Perspectives of Discharge Transitions of Seniors with Dementia

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Hospital discharge transitions can be challenging for seniors and their caregivers. Seniors with dementia are particularly vulnerable and are at increased risk for adverse outcomes from poorly executed hospital to home discharge transitions. Family caregivers play a vital role in supporting seniors with dementia by coordinating care among healthcare providers across the continuum of care. Research suggests there is significant opportunity for improvement in hospital discharge processes to ensure that patients with dementia and their family caregivers are prepared to resume care at home after hospital discharge. Family caregivers of hospitalized patients with dementia continue to report unmet needs and the extent to hospital discharge interventions are provided and how they are perceived by family caregivers of patients with dementia is unknown.

Guided by Meleis' middle-range theory of transitions, a critical incident technique study was designed to explore family caregiver perceptions of the hospital discharge process for seniors with dementia. Five categories of healthcare provider activities were identified as important to the hospital discharge process for persons with dementia. *Providing person-centered dementia care* involved *recognizing dementia* in the patient and the importance of *taking a different approach. Getting on the same page* emphasized the crucial role of communication and involved *seeing a capable person* and *knowing the plan*. Caregivers expressed concern for *Maximizing function* and strong enough to go home. *Managing medications* was critical to ensure behavioral symptoms of dementia were well managed. *Post-discharge support* involved *getting needed information, arranging for services after discharge, and calling for help.* These categories are consistent with the literature regarding hospital to home discharges for seniors and their caregivers. Family caregivers of hospitalized patients with dementia have additional needs beyond those of typical patients and collaboration with healthcare providers is vital to ensure patient needs are met. These findings highlight the importance of person-centered care delivery so that hospital discharge processes are tailored to the unique circumstances of each patient and caregiver.

Table of Contents

Chapter 3 Methodology 91

List of Tables

List of Figures

Chapter 1: Introduction to Study

PURPOSE

Adults over age 65, otherwise termed seniors, represent 15% of the population but account for 48% of hospital discharges (Mezey et al., 2004). Up to 40% of hospitalized seniors have cognitive impairment, though not always recognized, putting them at increased risk of preventable adverse events and hospital-acquired complications (Boustani et al., 2012). All seniors are vulnerable during the transition from hospital to home and are at risk for poor outcomes (Naylor, Bowles, & Brooten, 2000) but hospitalized patients with cognitive impairment are especially vulnerable (Naylor et al., 2007). Persons with Alzheimer's disease and related disorders are unable to be full participants in their medical care because of cognitive impairments and most rely on the support of family caregivers (Drebing & Harden, 2006).

Family caregivers play a critical role in patients' recovery by providing practical assistance and emotional support in the post-hospital phase, even when the patient's care needs are physically challenging or technically complicated (Gibson, Kelly, & Kaplan, 2012; Rose, Bowman, & Kresevic, 2000). Hospitalized patients who are seniors are rarely restored to their prior level of health by the day of discharge and many depend on family caregivers for post-hospital care (Wakefield & Holman, 2007). This is particularly true for hospitalized patients with dementia who are at increased risk of several adverse events such as physical deconditioning, incontinence, falls, and inadequate nutrition (Fick

& Foreman, 2000) and have higher rates of rehospitalization after discharge (Epstein-Lubow & Fulton, 2012).

Avoiding post-discharge complications in the home setting depends on the patient's and family caregiver's ability to implement the discharge treatment plan (Coleman & Berenson, 2004). The hospital discharge transition is a complex process characterized by uncertainty (Michels, 1988) and worry (Bull, 1992) for patients and family caregivers. Hospitalizations are especially problematic for family caregivers when the hospitalized patient has dementia. Research reveals that family caregivers experience issues with health care providers' ability to address the patient's needs, lack of engagement with the family, little to no care coordination and discharge planning, and unmet expectations in care delivery (Bauer, Fitzgerald, & Koch, 2011). Family caregivers play an important advocacy role in the hospital discharge process by communicating with healthcare providers about the home environment, the caregiving situation relative to the patient's post-discharge needs, and advocating for patients when questions or problems arise (Coleman, 2003). Healthcare providers often underestimate the importance of involving family caregivers in the hospital discharge process. In one study, 46% of family caregivers reported little to no involvement in the discharge process (Bull, Hansen, & Gross, 2000a). Further, healthcare providers often don't recognize the significant disruption a hospitalization represents for the patient with dementia and the family caregiver who experience loss of daily routines and medication schedules, interrupted community services, and a chaotic hospital environment (Zanjani, 2015).

Preparing the patient and family caregiver for hospital discharge is a key responsibility of healthcare providers yet family caregivers consistently emphasize the need for better communication and more information about the post-discharge treatment plan (Aumann, Galinsky, Sakai, Brown, & Bond, 2010). Many post-discharge issues involve poor communication with health care providers about patients' ongoing care needs after discharge including whom caregivers should contact with questions or problems (Dossa, Bokhour, & Hoenig, 2012). Inadequate preparation for hospital discharge has significant safety consequences for seniors particularly related to medication errors and failures of self-management that may result in rehospitalization (Greenwald & Jack, 2009).

Family caregivers have expressed dissatisfaction with hospital care related to poor communication, lack of care coordination, and little input into the discharge planning process (Whittamore, Goldberg, Bradshaw, & Harwood, 2014). The challenge of the hospital discharge transition was eloquently described by a nursing school dean who was suddenly thrust into a care management role for her spouse after he suffered a brain stem stroke (Swan, 2012). The author noted the complexity of care coordination, receipt of too much information to absorb at the time of discharge, and difficulties scheduling follow up appointments with specialists. She also emphasized the importance of evaluating patient and family readiness to manage care prior to discharge, noting: "How can we expect not-yet-well people to suddenly begin managing all of the complex medical and personal issues that, just the day before, were being handled by an entire team of trained professionals?” (Swan, 2012, pg. 2582). Efforts have been made to improve the hospital experience for patients with dementia and their family caregivers by providing more information and involving family caregivers to a greater extent (Sewter, Jones, Hart, & Dyer, 2014).

Evidence suggested that there is substantial room for improvement in discharge planning for family caregivers of hospitalized patients with dementia (Dewing & Dijk, 2016). Over seventy distinct discharge-related interventions have been identified and some have been shown to be effective in preventing adverse outcomes but significant gaps remain in the care of hospitalized patients with dementia (Chenoweth, Kable, & Pond, 2015). The extent to which beneficial discharge interventions have been adopted into current hospital processes is not clear and little is known about how discharge interventions are received (directly or indirectly) by family caregivers of hospitalized patients with dementia.

The purpose of this study is to explore family caregiver perspectives on hospital discharge processes influenced their ability to support the patient with dementia after hospital discharge. An improved understanding of the unique needs and preferences of family caregivers of hospitalized patients with dementia may inform interventions to better prepare family caregivers for managing care at home and preventing post-discharge complications.

BACKGROUND AND SIGNIFICANCE

As a result of the aging population, the prevalence of dementia is on the rise. Approximately 5.3 million people of all ages and 5.1 million people over age 65 have been diagnosed with Alzheimer’s disease or related disorders (Zhanlian, Coots, Kaganova, & Wiener, 2013). The oldest old are at highest risk with over one third of persons over age 85 have some type of dementia. Unless a cure is found, by 2050 the number of people age 65 and older with Alzheimer’s disease could triple to an estimated 13.8 million people worldwide (Alzheimer’s Association, 2015).

The prevalence of dementia among community-dwelling seniors is approximately 12% and this group is at significantly higher risk for potentially avoidable hospitalizations and emergency room visits than community-dwelling seniors without dementia (Feng, Coots, Kaganova, & Wiener, 2014). One study of community dwelling seniors revealed that seniors with dementia had a hospitalization rate more than three times that of seniors without dementia. Two-thirds of the seniors with dementia were hospitalized once and nearly half were hospitalized more than once in the year prior to the study (Rudolph et al., 2010). According to the Alzheimer’s Association (2015), Medicare beneficiaries with dementia are more likely to have other chronic health conditions than seniors without dementia. Further, average annual per beneficiary spending for inpatient hospital care is 2.5 times higher for beneficiaries with dementia than those without ($11,370 vs. $4,571). Escalating healthcare costs, particularly expensive acute hospital care, is of interest to researchers worldwide who have noted similar trends in increased healthcare utilization for community-dwelling seniors with dementia (Tolppanen et al., 2015) and poorer health outcomes in this vulnerable population (Travers, Byrne, Pachana, Klein, & Gray, 2014).

In the United States, health care for the aging population has caused increased financial pressure on Medicare, the largest payer of healthcare services in the US (Qian, Russell, Valiyeva, & Miller, 2011). Changes to Medicare payment policy for inpatient care has resulted in the development of cost-cutting strategies such as pressuring physicians to discharge seniors "quicker and sicker," or earlier in the recovery phase (Grimmer, Moss, & Gill, 2000). Shorter hospital length of stay means that healthcare providers have fewer days for discharge planning and less time with patients and family caregivers for discharge teaching (Weiss et al., 2007). Despite the evidence pointing to increased care needs for seniors after discharge, healthcare providers often overlook or underestimate the importance of family caregivers in providing post-hospital discharge support (Bull et al., 2000a). Failure to involve family caregivers, especially those supporting a hospitalized patient with dementia, in the hospital discharge process increases burden on family caregivers and has significant healthcare system implications.

Seniors are vulnerable to adverse health outcomes when the hospital discharge process fails to adequately prepare seniors and their family caregivers for care management in the post-discharge period (Naylor, Stephens, Bowles, & Bixby, 2005). One in five hospitalized patients experiences an adverse event after discharge, defined as an injury resulting from post-hospital medical management (Forster, Murff, Peterson, &

et al., 2003). Seniors are particularly susceptible to medication-related problems as they or their caregivers resume responsibility for home medication management (Foust, Naylor, Boling, & Cappuzzo, 2005). Medication regimens can change significantly while patients are hospitalized (Mansur, Weiss, & Beloosesky, 2008) and these changes may be confusing for seniors and caregivers, particularly when medications the patient was accustomed to taking are discontinued (Harris, Sridharan, Landis, Howell, & Wright, 2013). These issues are magnified in hospitalized patients with dementia who are at particularly high risk for delirium (Ahmed, Leurent, & Sampson, 2014).

Discrepancies between the hospital medications list and the medications the senior is actually taking are common, with one study reporting an average of 3.3 discrepancies per senior and at least one discrepancy identified for 94% of seniors (Corbett, Setter, Daratha, Neumiller, & Wood, 2010). Hospitalized patients with dementia are particularly sensitive to disruptions in the complex medication regimens needed to manage behavioral symptoms throughout the day and evening (Deeks, Cooper, Draper, Kurrle, & Gibson, 2015). Increased involvement of family caregivers in discharge preparation may help prevent medication-related adverse events after discharge but research shows that even basic interventions, such as a medication list, are not consistently provided to seniors and their caregivers (Knight, Thompson, Mathie, & Dickinson, 2013).

Family caregivers are described as the “backbone” of long-term care throughout the landmark report Retooling for an Aging America: Building the Healthcare

Workforce (IOM, 2008). This report emphasized the vital role of informal family caregivers as part of the healthcare workforce in caring for the elderly. Family caregivers provided an estimated $450 billion in uncompensated care to seniors in 2009 (Feinberg, Reinhard, Houser, & Choula, 2011). Over 42% of employed Americans, almost 55 million employees, have helped a senior with some aspect of care that the care recipient found difficult or impossible to do themselves (Aumann et al., 2010). The majority of working caregivers (69%) report making work changes to accommodate caregiving responsibilities (Feinberg et al., 2011). Providing care to seniors in poor health is a stressful experience that has negative effects on family caregivers' physical health and emotional well-being (Pinquart & Sörensen, 2003). Some spousal caregivers of seniors also have health issues that impact their ability to provide post-hospital care (Grimmer et al., 2000). Spousal hospitalization is associated with an increased risk of family caregiver mortality, especially for elderly couples living below the poverty line (Christakis & Allison, 2006). Family caregivers may neglect their own health, particularly if the caregiving situation is physically or emotionally demanding (Beesley, Price, & Webb, 2011). This is also true for caregivers of persons with dementia, who are more likely to report their health as fair or poor and are more likely to say that their health has worsened because of caregiving than caregivers of persons without dementia (Alzheimer's Association, 2015). One study of healthcare utilization found that 24% of caregivers of persons with dementia had an emergency room visit or hospitalization in the previous six months (Schubert et al., 2008). Caregivers of persons with dementia report increased stressors, depression, and sleep disturbances when the care recipient has behavioral symptoms and when the care recipient is hospitalized (Bradshaw, Goldberg, Schneider, & Harwood, 2013).

According to 2003-2004 claims data, 11.8 million Medicare beneficiaries experienced unplanned readmissions within 30 days of discharge, resulting in over $17 billion in potentially avoidable Medicare cost (Jencks, Williams, & Coleman, 2009). Readmissions within 30 days of discharge may be attributed to failures in self-management at home (Proctor, Morrow-Howell, Li, & Dore, 2000). Healthcare utilization measures such as emergency department visits and readmissions are commonly used to evaluate the effectiveness of hospital discharge processes and care coordination (Coleman & Boult, 2003). Recent research literature has described the effectiveness of interventions aimed at improving transitional care, defined as "a set of actions designed to ensure the coordination and continuity of healthcare as patients transfer between different locations" (p. 556) with an emphasis on "handoffs" or communication among everyone involved in the patient's care (Coleman & Boult, 2003). Evidence suggests that seniors with dementia also benefit from these evidence-based transitional care interventions (Naylor et al., 2014). Failure to adequately prepare patients and caregivers for hospital discharge has significant healthcare system implications. Several studies have demonstrated the benefits of family caregiver involvement in the hospital discharge process (Bull et al., 2000a).

In an attempt to improve hospital discharge processes and prevent avoidable readmissions for all seniors, the Patient Protection and Affordable Care Act of 2010 (ACA) requires the Centers for Medicare & Medicaid Services (CMS) to establish a hospital readmissions reduction program. This pay-for-performance program penalizes hospitals with higher than average readmission rates through payment rate cuts and funds improvement initiatives. The Community-Based Care Transitions Program established by Section 3026 of the ACA provides up to $500 million to health systems and community organizations that implement at least one transitional care intervention.

One recent large-scale improvement effort, the Transitions in Care – Quality Improvement Collaborative (TC-QuIC) focused on hospital strategies to engage caregivers more effectively in post-discharge needs assessment and planning, training caregivers on tasks and what to expect, coordinating care on the day of discharge, communicating with other providers for post-discharge hand-offs, and ensuring the medication list is accurate through a process of medication reconciliation (Levine, Halper, Rutberg, & Gould, 2013). This project was a direct outgrowth of the “Next Step in Care” campaign to change healthcare provider behavior in order to ensure that family caregivers are involved in all aspects of transitions from one setting to another (Levine et al., 2013). These initiatives do not focus specifically on the unique needs of hospitalized patients with dementia or their family caregivers and are designed to benefit vulnerable hospitalized patients of all ages.

Although these efforts are promising, the vast majority of seniors and their family caregivers do not receive evidence-based discharge interventions when going home from the hospital. Despite ongoing hospital improvement initiatives hospital to home discharge remains high risk and problem prone for seniors and those with ongoing complex care needs such as persons with dementia (Coleman, 2003). Family caregivers witness discharge problems first hand and may possess valuable insights as to why some hospital discharge processes and interventions are more effective in some situations than others. The extent to which family caregivers of persons with dementia perceive they are benefitting from improvements in hospital discharge processes is not known.

STATEMENT OF PROBLEM AND RESEARCH QUESTIONS

Preparing patients to go home from the hospital is a multi-phase process that involves the assessment of post-discharge needs, discharge planning, and education or discharge instructions (Shepperd et al., 2010). Healthcare provider communication of clear and relevant information is the foundation for successful implementation of the patient's treatment plan at home (Maloney & Weiss, 2008). Caregiver burden and anxiety is decreased when healthcare providers involve caregivers in discharge planning and discharge preparation (Bauer, Fitzgerald, Haesler, & Manfrin, 2009). As hospital discharge processes evolve over time, it is important to determine the extent to which healthcare providers engage patients and family caregivers in discharge planning and preparation. The purpose of this study is to explore family caregiver perspectives on hospital discharge processes for seniors with dementia and how discharge preparation activities and other factors influenced their ability to provide care after hospital discharge.

Research Questions

1) How do family caregivers of hospitalized patients with dementia describe the hospital discharge process?
2) Who was involved in the hospital discharge process and what actions were taken to prepare the patient with dementia and the family caregiver for hospital discharge?
3) How do family caregivers describe the influence of healthcare provider behaviors on the family caregiver's confidence, coping, and ability to support the patient with dementia after hospital discharge?
4) How do family caregivers describe the personal factors that facilitated or inhibited their ability to their ability to support the patient with dementia after hospital discharge?

SIGNIFICANCE TO NURSING

Individualized care is the first tenet of nursing practice (American Nurses Association, 2010) and nurses are ethically bound to consider the uniqueness of every individual (American Nurses Association, 2001). Preparing patients for discharge is a core competency of nurses yet patients and caregivers continue to report feeling unprepared and experience unmet needs after discharge (Bull & Jervis, 1997; Bull, Jervis,

& Her, 1995; Holland, Mistiaen, & Bowles, 2011). This study may sensitize nurses to the family caregiver perspective, the unique needs of hospitalized patients with dementia and their caregivers, and could inform further research to develop and test strategies to improve family caregiver support during the hospital discharge process. As providers of information and education, nurses must be aware that family caregivers may find it difficult to provide care and needed treatments based on instructions given at the hospital once they are alone with the patient in the home environment (Levine, Reinhard, Feinberg, Albert, & Hart, 2003). When the patient treatment plan involves the use of medical equipment, such as feeding pumps and drug delivery devices, nurses must recognize and plan for the additional support family caregivers need to reduce the physical, emotional, social, and financial burdens of providing technology-dependent care in the home (Winkler, Ross, Piamjariyakul, Gajewski, & Smith, 2006). With an improved understanding of hospital discharge processes from the family caregiver perspective, nurses can adapt their approach and individualize interventions for various circumstances such as patients with care needs that involve frequent, complex, or time-consuming treatments, family caregivers who do not live with the patient, or working family caregivers (Popejoy, 2011).

Nurses have played a key role in healthcare reform, quality improvement, and patient safety since the mid-nineteenth century when Florence Nightingale strenuously advocated for improved hospital conditions (American Nurses Association, 2010). Supporting patients and families during care transitions is a central role of nursing

(Meleis, 2000) and nurses are ethically obligated to collaborate with patients, families, and other healthcare providers to ensure that care delivery is safe, effective, and individualized (American Nurses Association, 2001).

CONCEPTUAL ORIENTATION

Hospital discharge processes have evolved over the years and several research interventions focused on preparing and supporting the patient and family caregiver have shown positive outcomes for seniors (Coleman, Parry, Chalmers, & Min, 2006). However, the current extent of family caregiver involvement in hospital discharge processes for persons with dementia is not known. Therefore, a qualitative research design was chosen as the best method of exploring the family caregiver perspective about the hospital discharge process. In qualitative approaches to research, theory can provide the nurse researcher with an organizing framework to guide study questions and data analysis (Wu & Volker, 2009). As such, Meleis' middle range theory of transition provides an ideal conceptual framework for this study. Middle range theories describe, explain, or predict phenomena and are specific enough to inform research designs and guide clinical practice (Mars & Lowery, 2009). Transitions are conceptualized as a multidimensional complex process triggered by a significant change or event (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). The facilitation of healthy transition processes through therapeutic interventions is a key focus of nursing practice (Meleis & Trangenstein, 1994). Healthy transitions are characterized by positive response patterns such as effective coping, feelings of connection, and role mastery (Meleis et al., 2000). Family caregiver interpretations of the patient’s post-discharge needs, role expectations, and relationships are congruent with the philosophies of symbolic interactionism, social learning and role theories that are the underpinnings of transitions theory (Meleis, 2010).

When an older adult goes home from the hospital, a number of dynamic and reciprocal role changes for the patient and family caregiver take place, a process described as “role tuning” (Shyu, 2000). During the transition from hospital to home, seniors and family caregivers establish a new routine through trial and error (Bull, 1992). This process is further complicated when the hospitalized patient has dementia (Naylor et al., 2007). The role of the nurse is to provide therapeutic interventions that are selected based on the patient and family caregiver’s unique situation, transition conditions, roles, and relationships allowing the nurse to individualize care according to the factors that are most likely to facilitate the hospital discharge transition (Schumacher, Jones, Meleis, Swanson, & Tripp-Reimer, 1999).

Major concepts of transitions theory include the types and patterns of transitions, the properties of transition experiences, the conditions that facilitate or inhibit the transition, nursing therapeutics, and patterns of response (Meleis et al., 2000). The types of transitions include developmental, situational, health and illness, and organizational. Patterns of transitions include single, multiple, sequential, and simultaneous transitions that may be related or unrelated. The properties of a transition experience consist of awareness that change is happening, engagement in the transition process, change and difference, time span , and critical points and events (Meleis et al., 2000). A pilot study of awareness of discharge date for chronically critically ill older adults found that caregivers were aware of the discharge date an average of 1.4 days prior to discharge. This was more than double that of nurses, who became aware of the discharge an average 0.6 days prior to discharge (Lipson, Kelley, Higgins, & Daly, 2006). If this finding is typical of other large hospitals in the US, then little time is available for discharge preparation and teaching. The hospital discharge process, changing care needs, and time span are linked to the critical points and events described by transitions theory.

Transitions theory is useful in understanding patient and caregiver patterns of response; that is, how process indicators and outcome indicators are influenced by hospital discharge interventions (Meleis et al., 2000). Process indicators, such as perceived readiness for discharge, are measured while the transition is taking place to evaluate how the process is going at different points in time. Outcomes indicators, such as mastery and identity reflect the concept that people are changed by the transition experience as roles and relationships change. The transition is complete when the patient and caregiver reach a new period of stability or “a new normal.” Caregiver outcomes include developing confidence and coping with post-discharge care needs. Early rehospitalization is a common outcome measure of hospital discharge processes because it may reflect failure to adequately prepare patients and caregivers for management at home.

Parker and colleagues (2002) identified over 70 distinct discharge interventions including assessment of patient needs for post-acute care, developing a discharge plan, and preparing the patient and family for discharge in various combinations. Clear, accurate, and timely communication promotes positive outcomes (Meleis, 2010). Role supplementation is an important nursing intervention in which expectations are clarified and the information needed for effective self-care is reviewed (Schumacher & Meleis, 1994). Discharge teaching is the most common discharge intervention to prepare patients for hospital discharge (Shepperd et al., 2013) and provides an opportunity for patients and family caregivers to ask questions specific to the patient's situation. The quality of discharge teaching is a significant predictor of satisfaction and feelings of discharge readiness (Bobay, Jerofke, Weiss, & Yakusheva, 2010; Bull, Hansen, & Gross, 2000b; Weiss et al., 2007).

Transition conditions are the personal factors that may facilitate or inhibit successful patterns of response. These factors include health conditions such as dementia and related factors, such as behavioral symptoms, that can influence patient and caregiver outcomes. Nurses increase the effectiveness of therapeutic interventions by individualizing care based on these personal factors (Meleis, et al., 2000). For family caregivers transition conditions include personal conditions (such as preparation, knowledge, health literacy, attitudes, beliefs, and meaning), community resources (such as volunteer services and home delivered meals), and societal factors (such as health policy and benefit coverage criteria) (Meleis et al., 2000). The influence of these factors becomes evident during and after the hospital discharge process, especially if the patient and caregiver are not prepared to manage care at home or don't know whom to contact with problems or concerns. Community and societal conditions also influence transitions including medical and hospital culture. A major societal factor influencing seniors and their caregivers is Medicare payment policy regarding eligibility for hospital and post-acute care.

Medicare is the largest payer of healthcare services for older adults and the largest category of Medicare spending is inpatient care. The implementation of the prospective payment system (PPS) started a cascade of change in 1983 that significantly influenced health care delivery in hospitals, post-acute-care providers, and physician practices. Under PPS, hospitals were paid based on fixed payments for diagnosis related groups (DRGs) no matter how much it cost to care for the patient or how many days the patient was in the hospital. The decreased Medicare reimbursement forced hospitals to control costs by adopting a variety of clinical practice changes aimed at decreasing hospital length of stay which resulted in a higher percentage of seniors discharged in an unstable condition (Kosecoff et al., 1990), or "quicker and sicker." The average length of hospital stay for seniors has decreased by more than half since the implementation of PPS, from over 11 days in 1982 to 4.9 days in 2010 (CMS, 2013). The shortened hospital stay left less time for hospital staff to involve family caregivers in discharge planning and prepare them for care in the home (Bull et al., 2000a).

The increased acuity of discharged seniors also led to significant growth in the need for home health and rehabilitation in skilled nursing facilities (SNF) as families were less able to cope with seniors' increased care needs (Foust, Vuckovic, & Henriquez, 2012). After implementation of PPS, Medicare spending on post-acute care services tripled for home health and quadrupled for SNF rehabilitation (McCall, Korb, Petersons, & Moore, 2003). Nursing home admissions more than tripled for patients in the first weeks after hospital discharge as families sought additional care options until the patient was more fully recovered (Qian et al., 2011). To control costs in post-acute settings further policy changes restricted access to post-acute care and decreased the frequency and duration of services for seniors and family caregivers after hospitalization (McCall et al., 2003).

Changing Medicare reimbursement also had significant effects on inpatient and outpatient physician practice patterns as hospitals increased pressure on physicians to discharge hospitalized patients as soon as possible. The hospitalist model emerged as an effort to improve the efficiency of medical care delivery while improving patient safety (Wachter & Goldman, 1996). For the first time, physicians were available in hospitals full-time to respond quickly to changes in patient condition and to write discharge orders throughout the day as patients' lab and radiology reports became available. Primary care physicians also realized gains in efficiency as they were no longer responsible to make hospital rounds and could see more patients in the office. As these programs became an established part of the healthcare system, the patient experience of care became increasingly fragmented. Communication with the patients’ primary care physician at the time of admission and at discharge has been recognized as vital to continuity of care (Pham, Grossman, Cohen, & Bodenheimer, 2008). Although transitional care protocols have been developed to ensure continuity of patient health information (Arora et al., 2009), care coordination is often left to family caregivers who are expected to manage complex issues on their own with little support in the home (Swan, 2012).

Caregiver impressions of significant events during the hospital discharge transition are important to study because caregivers may offer valuable insights into the factors that enhance the effectiveness of discharge interventions under specific transition conditions. Transitions theory provides a useful framework to understand how discharge interventions contribute to positive discharge outcomes for seniors and family caregivers. The critical points and events in a transition process are associated with an increased awareness of and active involvement in the transition process. This study focused on family caregivers’ perspective of the hospital discharge process and discharge preparation activities for senior with dementia. Caregivers were asked about significant discharge events and discharge-related interactions with healthcare providers and how these interactions influenced the hospital discharge process.

DEFINITIONS

Seniors

Seniors are defined as people 65 years of age or older.

Family caregiver

The family caregiver is defined as a relative or close friend who served as the major support person for a senior with dementia who went home from the hospital. Family caregivers are unpaid and engage in activities such as assisting with medication management, monitoring for signs of worsening condition, encouraging adherence to the treatment plan for activity and diet, and encouragement of or assistance with health promotion or health maintenance activities.

Dementia

Dementia is defined broadly and includes any type of cognitive impairment that limits the ability of a hospitalized senior to independently engage in self-care after hospital discharge.

Home

Home is defined broadly to include any residential setting where a hospitalized patient may be discharged to such as a private home, a personal care home, or assisted living.

Acute care hospitalization

Acute care hospitalization refers to admission to a medical- surgical hospital for an inpatient stay and does not include admission to long-term acute care hospitals, rehabilitation facilities, day hospitals, or psychiatric facilities.

Hospital discharge process

The hospital discharge process begins during hospitalization and consists of the activities and interventions delivered (or encouraged) by healthcare providers to prepare the senior for discharge home. The process typically includes a discharge needs assessment, development of a discharge plan that includes ordering home equipment if needed, education and discharge instructions with activity recommendations and recommended follow-up with community healthcare providers (Weiss et al., 2007). The family caregiver may not be involved in the hospital discharge process and may only become aware of discharge-related activities during interactions with the patient. The hospital discharge process ends when the patient leaves the hospital.

Discharge preparation activities

Discharge preparation activities refer to the specific actions or behaviors carried out or encouraged by healthcare providers to facilitate the hospital discharge process such as needs assessment, discharge planning (including a plan for post-discharge follow-up), and providing education, information, resources, and instructions prior to discharge (Shepperd et al., 2010).

Significant discharge events

Significant discharge events are the salient situations or interactions that family caregivers recall as most influential on the outcome of the hospital discharge process. These events may precipitate changes in family caregiver awareness, behavior, or interactions with healthcare providers (Meleis et al., 2000). In this study, the outcome of interest is the family caregiver's confidence, coping, and ability to support the senior with dementia after hospital discharge. The outcome of the hospital discharge process may not be evident until sometime after the senior and family caregiver are at home, for example when a question or concern arises or a complication occurs.

ASSUMPTIONS

The following assumptions guided this study.

1) The hospital discharge process includes the actions of healthcare providers who engage in discharge preparation activities prior to the senior's discharge home from the hospital.
2) Family caregivers may not experience the hospital discharge process directly and may become aware of discharge preparation activities indirectly through interactions with the senior with dementia.
3) Family caregivers are able to recall specific discharge preparation activities and discharge-related interactions with healthcare providers in order to identify significant discharge events (Schluter, Seaton, & Chaboyer, 2008).
4) Family caregivers are able to judge whether the discharge preparation activities facilitated or inhibited the discharge process based on how well the senior and caregiver were able to manage at home after discharge.

5) Family caregivers are able to describe personal factors that facilitated or inhibited their confidence, coping, and ability to support the senior after discharge home from the hospital.
6) Transitions theory provides a useful framework for exploring hospital to home transitions in seniors with dementia from the perspective of family caregivers.
7) Using critical incident technique, the researcher can elicit the family caregiver perspectives of the hospital discharge process for seniors with dementia.

LIMITATIONS

This study has several limitations. First, findings from qualitative studies are not generalizable to a population but do reveal important insights into complex phenomena such as the hospital discharge transition process for seniors with dementia and their caregivers. Further, family caregiver recollections may not be wholly accurate and memories of situations and discharge interventions may represent a composite of experiences, particularly if the senior experienced multiple hospitalizations over a period of time. Critical incident technique has been demonstrated to be effective in eliciting perceptions of nursing care even when participants summarize overall experiences into a description of a single incident (Norman, Redfern, Tomalin, & Oliver, 1992). In accordance with critical incident methodology, the researcher attempted to recruit a heterogeneous group of family caregivers who had experienced a variety of hospital discharge situations in order to elicit diverse significant events and ultimately identify the maximum number of discharge preparation activities. Despite these limitations, this study clarified which aspects of discharge preparation activities facilitated and which hindered caregivers' ability to provide post-discharge care to seniors with dementia.

SUMMARY

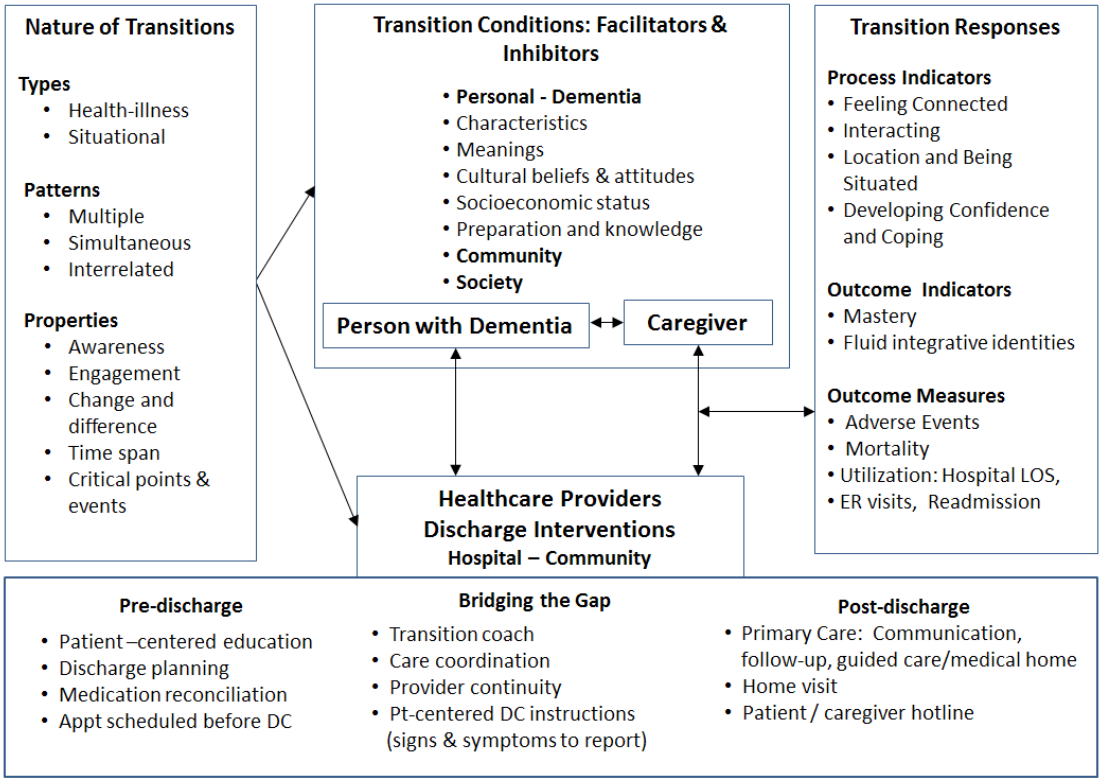
Nurses facilitate high quality care and ease caregiver burden through delivery of therapeutic interventions such as patient and caregiver education and emotional support and instruction (Donelan et al., 2002). Hospital patients, particularly those with dementia, often have complex care needs after hospital discharge and family caregivers must balance the positive aspects of being in the home environment with the challenge of administering complex treatments or therapies at home. Transitions theory provides a framework to understand significant events in the discharge process from the family caregiver perspective and how those discharge interventions influence patient and caregiver experiences. An exploration of caregiver perceptions of discharge interventions may provide valuable insights into what caregivers find most helpful and under which circumstances. Such information would be useful in developing and testing approaches to provide highly effective discharge interventions and improve hospital discharge processes and outcomes.

Chapter 2: Review of the Literature

INTRODUCTION

The focus of this chapter is to summarize the large body of research on hospital-to-home discharge processes for seniors and their caregivers. The literature review method proposed by (Rew, 2011) and uses transitions theory (Meleis, 2000) as an organizing framework. To better understand the existing literature on hospital to home transitions research for seniors with dementia from the caregiver perspective, this review was conducted in two phases. Phase I cast a broad net and included research on all seniors going home from the hospital, not just those with dementia. This body of literature was explored using the framework of Meleis' transitions theory. Reviews of intervention-level research represented the current knowledge on nursing therapeutics and qualitative and quantitative research revealed how transition properties, transition conditions, and patterns of response for the senior and caregiver were represented in the literature. Phase II focused specifically on discharge-related interventions for family caregivers of hospitalized patients with dementia. This two-phase approach informed the development of the Hospital to Home Discharge Transition Model for Family Caregivers of Seniors with Dementia, Figure 1.

Figure 1. Hospital to Home Discharge Transition Model for Seniors with Dementia



The research questions to be answered by this review are:

1) To what extent are caregivers described or included in systematic reviews of hospital discharge interventions for seniors?

2) What is the nature of qualitative literature of hospital-to-home discharges of seniors and their caregivers from the transitions theory perspective?

3) What are the theoretical underpinnings and variables of interest in non-experimental quantitative research of hospital-to-home discharges of seniors and their caregivers?

4) What is the nature of intervention-level research of caregiver interventions to facilitate the hospital-to-home discharge transitions of seniors?
5) What is the nature of intervention research for family caregivers supporting hospitalized seniors with dementia or cognitive impairment during the hospital to home discharge transition?

Method

An electronic search was conducted to identify relevant research literature. Inclusion criteria were: English-language articles of seniors discharged from general medical-surgical hospitals to the home setting published in peer-reviewed journals between January 2000 and December 2013. This time frame was selected to reflect current healthcare industry factors such as technological advances, the aging population, and government payment policies for acute care. Exclusion criteria were discharges from other settings such as psychiatric hospitals, rehabilitation hospitals, ambulatory surgery centers, long term care facilities, and non-US studies because of healthcare systems differences. To capture the broad base of nursing therapeutics for all seniors going home from the hospital the following search terms were selected in consultation with a science librarian: hospital*, discharg*, caregiv*, and transition*, and subject headings "after care", "continuity of care", "patient discharge," and "discharge education." The databases searched were: PubMed, Cumulative Index to Nursing and Allied Health Literature, MEDLINE, Cochrane Database of Systematic Reviews, Academic Search Complete, and Web of Science. Limiters were applied where possible to narrow the search results in accordance with the inclusion criteria. Electronic searching was supplemented by bibliographic searches of reviews, articles on related topics such as coordination of care in gerontology, family eldercare, and government quality improvement resources on care transitions. Search results were exported to EndNote X5 citation management software and duplicates were removed.

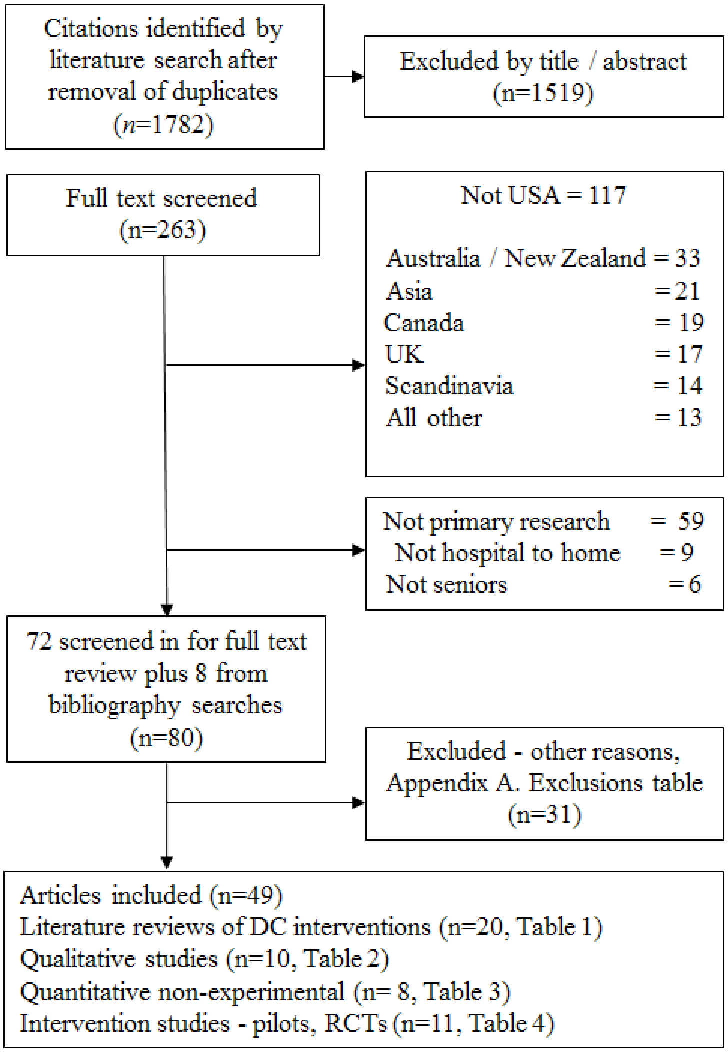
A separate second search focused on hospital patients with dementia and their caregivers was conducted for the timeframe of January 2000-December 2014. The purpose of this review was to identify literature specific to hospital to home discharge interventions for seniors with dementia to answer the 5th question of this review: what is the nature of intervention research for family caregivers supporting hospitalized seniors with dementia or cognitive impairment during the hospital to home discharge transition? The aforementioned search strategy was implemented with the addition of the search terms “dementia,” and “cognitive impairment.”

First, existing reviews of the literature on discharge interventions for seniors were reviewed to determine the extent to which family caregivers have been involved in previous research. Next, published qualitative and non-experimental research studies of hospital discharges involving seniors and caregivers were evaluated and used to develop a coding scheme based on transitions theory concepts. A code sheet and code book were developed from the concepts identified in the qualitative and non-experimental literature and are included in the literature review supplement Appendix A. The code sheet was used to extract data from intervention-level research on hospital discharge of seniors that targeted family caregivers. Research quality was evaluated using a scoring system adapted from Brown (1991).

RESULTS

The initial Phase I search results are outlined in Figure 2.

Figure 2. . Hospital to Home Summary of Literature Search and Article Selection



After screening titles, abstracts, and full-text articles, 72 articles ultimately screened in for review. An additional eight studies were identified through bibliographic methods. Thirty one studies were excluded because they did not meet the literature review inclusion criteria. Common reasons for exclusion included study samples that were not older adults, caregivers were not a focus of study, or the transition occurred in settings other than hospital to home. Excluded studies for Phase I and Phase II with the rationale for exclusion were tracked (Appendix A.) The remaining 49 studies fell into the following categories: literature reviews of discharge interventions for seniors (20 reviews), qualitative (10 studies), non-experimental quantitative (8 studies), intervention research (11 studies), and dementia caregiver interventions (4 studies).

Phase II of the literature review, specific to interventions for family caregiver of hospitalized dementia patients, identified 427 unique publications. More than half of these studies were international research, highlighting the significant interest in this topic around the world. After screening titles and abstracts, 39 studies screened in for review and an additional two studies were identified through bibliographic methods for a total of 41 studies. Of these, 3 were interventions targeted specifically for caregivers of hospitalized patients with dementia (Boltz, Resnick, Chippendale, & Galvin, 2014; McCauley, Bradway, Hirschman, & Naylor, 2014; Naylor et al., 2007).

REVIEWS OF THE LITERATURE

Literature reviews of hospital-to-home discharge interventions were examined to determine the extent to which caregivers were included in research studies hospital discharge transitions. Eighteen reviews were identified with electronic searches and two additional reviews were identified through bibliographic methods. The twenty reviews were evaluated according to the aim, methods, measures, findings and determine the extent to which family caregivers were involved in the research. A summary of the reviews is included in Table 1.

All twenty reviews cited issues with research quality, ranging from lack of blinding to failure to describe the comparison or usual care group. Quality issues such as lack of consistent reporting of standard deviations hampered efforts to calculate effect sizes and heterogeneity of interventions limited the ability to draw conclusions from the research. Seven reviews included only randomized clinical trials and the rest included pilot and quasi-experimental studies. These interventions were not tested in patients with dementia because cognitive impairment was a frequent exclusion criterion.

One source of heterogeneity was the different countries represented in the healthcare literature. Hospital to home transitions is an area of interest around the world as many countries work to balance healthcare needs of the persons aging with complex chronic conditions with available healthcare system resources. Although the experience of supporting a senior coming home from the hospital may be similar in any country, healthcare system and sociocultural differences are likely to influence patient and caregiver outcomes and limit comparability with the US healthcare system. Not all reviews reported the countries in which studies were conducted, but at least fifteen different countries were represented and the median number of countries per review was

Table 1. Literature reviews of hospital discharge interventions in older adults published between 2000-2013

Author(s)/ Year	Aim	Studies	Designs	Subjects	Conclusions	Caregiver Inclusion
Hyde, C. J., Robert, I. E., & Sinclair, A. J. (2000)	Eval effects of supported discharge	14 reports (9 studies) 4 countries publ between 1972-1995 US (1/9)	Experimental randomized and quasi-randomized studies	Pts aged 65+ w/ support in home within 1 wk of DC	Unable to reach conclusion on effects of supported discharge on hospitalization	One study included a measure of CG satisfaction w/ hospital at home Donald et al, 1995
Mistiaen, P., Duijnhouwer, E., & Ettema, T. (2000)	Conceptual model of factors influencing post-DC problems	87 studies 11 countries publ between 1990-1995 US (48/87)	8 qualitative 79 quant	Qualitative studies were all elderly; Quantitative Adults DC'd home from hosp ages 18+	PA problems relate to functional , emotional, health, and social status Influences are pt-related, care-related, and social factors	5 studies included CGs: Bull, 1994; Congdon, 1994; Jewell:, 1993; McWilliam, 1992; McWilliam & Sangster, 1994
Parker, S. G., Peet, S. M., McPherson, A., Cannaby, A. M., Abrams, K., Baker, R., . . . Jones, D. R. (2002)	Comprehensive review of DC and PA support programs for older adults going home	7 reports of 6 studies 2 countries publ between 1987-1999 US (4/6)	RCTs of CDP planning	Pts aged 56+ DC home from hosp Mean age: ≥70	1) Combined interventions were more effective than single interventions 2) Face to face interventions delivered in the hospital and at home were more effective	Authors note: "an almost complete absence of any pt- or carer- focused outcomes data," p. 144

AE=adverse events, AMI= acute myocardial infarction, CDP = comprehensive discharge planning, CG = caregiver, DC = discharge, hosp = hospital, ED= emergency department, Med Rec = medication reconciliation, IG = intervention group, PA=Post-acute, RA = readmissions; RCT = randomized controlled trials, RR = Relative Risk, SSD= Statistically significant difference, UC= usual care / control group

Table 1. Literature reviews of hospital discharge interventions in older adults published between 2000-2013

Author(s)/ Year	Aim	Studies	Designs	Subjects	Conclusions	Caregiver Inclusion
					than single setting or phone interventions 3) Education most effective for pts w/ diagnosis sensitive to self-management.	
Phillips, C. O., Wright, S. M., Kern, D. E., Singa, R. M., Shepperd, S., & Rubin, H. R. (2004)	Eval effects of combined CDP + PA support for heart failure pts.	18 studies, 8 countries, publ between 1966-2003 US (10/18)	RCTs of combined CDP with PA support.	Heart failure pts aged 55+	CDP combined with PA support lowered risk of hospital RA (RR 0.75), Cost savings $359 per patient for non-US studies, $536 for US studies	Not mentioned
Li, H., Melnyk, B. M., & McCann, R. (2004).	Eval effects of CG interventions on hospitalized pts	9 studies, publ between 1994-2003 US (7/9)	RCTs, Pilot studies, quasi-exp	Hospitalized patients age 60+	Interventions less effective when then focused on CG exclusively. Literature lacked theoretical base, limited generalizability	5 studies had interventions designed for CGs in the hospital discharge transition process. US (4/5)

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Table 1. Literature reviews of hospital discharge interventions in older adults published between 2000-2013

Author(s)/ Year	Aim	Studies	Designs	Subjects	Conclusions	Caregiver Inclusion
Chiu, W. K., & Newcomer, R. (2007)	Eval effects of nurse-assisted interventions DC'd to any setting	16 reports of 15 studies, 6 countries publ between 1996-2006 US (8/16)	RCTs of nurse-assisted transitional care interventions	Community-dwelling elderly	9/16 studies had some evidence that nurse assisted case management interventions reduce RA rates; 7/16 no SSD	Not mentioned
Mistiaen, P., Francke, A. L., & Poot, E. (2007)	Systematic meta-review to eval effects of interventions to reduce post-DC problems	15 high quality reviews – all international, none were US only reviews	Meta-analysis	Adults DC home from care settings, rehab or hospitals Elderly (6/15)	3/15 reviews noted positive effects for combined pre- and post- DC interventions Issue with heterogeneity of interventions	CG studies excluded
Jacob, L., & Poletick, E. B. (2008)	Qualitative systematic review	10 articles publ between 1997-2007 US (3)	Literature synthesis of various types of qualitative and quantitative studies and reviews	Adults over 17 independent in self-care who returned to pre-hospital living situation	Little evidence that enhanced discharge support is related to improved physical status; may have role in preventing or delaying hospital readmissions	2 studies included CGs: Lough, 1996; Naylor et al, 1994

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Table 1. Literature reviews of hospital discharge interventions in older adults published between 2000-2013

Author(s)/ Year	Aim	Studies	Designs	Subjects	Conclusions	Caregiver Inclusion
Bauer, M., Fitzgerald, L., Haesler, E., & Manfrin, M. (2009)	Identification practices that can improve DC planning and pt outcomes	Not described	Not described	"frail older patients" and CGs. No definition of frail and age unspecified	DC planning most effective w/: 1) Assessment of CG 2) Active early CG involvement 3) Adequate info / education 4) Communication w/CG 5) Provider communication 6) Ongoing support	Importance of CGs mentioned throughout review No specific CG studies referenced
Popejoy, L., Moylan, K., & Galambos, C. (2009)	Historical perspective on DP research for older adults	36 articles published 1990-2008 US Only	1990s mostly descriptive 1996 trend to RCTs (5), quasi-exp (4)	Pts aged 65+	The years of the review were characterized by health system change. Fragmentation and complexity make it difficult for pts and CGs to be aware of the services	12 Studies of CGs: Naylor, 1994; Brown, 1995; Arno et al., 1999; Bull et al., 2000a; Bull et al., 2000b; Bull et al., 2000c; Maglivy and Congdon, 2000; Huber and McClelland, 2003; Coleman et al., 2004; Naylor, 2004; Coleman et al., 2006

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Table 1. Literature reviews of hospital discharge interventions in older adults published between 2000-2013

Author(s)/ Year	Aim	Studies	Designs	Subjects	Conclusions	Caregiver Inclusion
Preyde, M., Macaulay, C., & Dingwall, T. (2009)	Systematic review of 10 years of DC planning interventions	25 studies, in 6 countries, publ between 1995-2005 US (6)	Meta-analysis of RCTs or quasi-exp studies	Pts aged 65+	• 8 studies w/ sig lower hospital LOS • 5 studies lower RA rates • 5 studies reported IG cost savings • No diff in pt mortality	CG involvement discussed in background, not a focus of the review
Shepperd, S., McClaran, J., Phillips, C. O., Lannin, N. A., Clemson, L. M., McCluskey, A., . . . Barras, S. L. (2010).	Eval effects of discharge planning for pts moving from hospital	21 studies, 7 countries, Published through 2009, US (10)	Cochrane Method ; RCTs	All ages, included pediatrics, long term care, psych, rehab, and hospital	Individualized, structured DC plan probably brings about a small reduction in hosp LOS, RA rates, and inc pt satisfaction The impact on health outcomes is uncertain	3 studies included CGs: Naylor, 1994 (US); Nazareth, 2001 (UK); Preen, 2005 (AUS)

AE=adverse events, AMI= acute myocardial infarction, CDP = comprehensive discharge planning, CG = caregiver, DC = discharge, hosp = hospital, ED= emergency department, Med Rec = medication reconciliation, IG = intervention group, PA=Post-acute, RA = readmissions; RCT = randomized controlled trials, RR = Relative Risk, SSD= Statistically significant difference, UC= usual care / control group

Table 1. Literature reviews of hospital discharge interventions in older adults published between 2000-2013

Author(s)/ Year	Aim	Studies	Designs	Subjects	Conclusions	Caregiver Inclusion
Kansagara, D., Englander, H., Salanitro, A., Kagen, D., Theobald, C., Freeman, M., & Kripalani, S. (2011)	Summarize validated RA risk prediction models	30 studies of 26 models, in 6 countries, Published through March 2011 US (23)	Model testing using prospective or retrospective admin data	14 studies included only pts aged 65+	Heterogeneity made synthesis difficult. Most current readmission risk prediction models perform poorly Models of pt factors are better predictors of mortality than RA risk	CG availability or social support was included in the final model in 2 studies, considered but not included in 1 model, not considered in 19 models
Naylor, M. D., Aiken, L. H., Kurtzman, E. T., Olds, D. M., & Hirschman, K. B. (2011)	Synthesize evidence on transitional care for chronically ill adults	21 RCTs, all US studies only	RCTs included transitional care interventions provided after ED visits and inpatient stays	Chronically ill adults, mean age 64.7 all studies, range 32-76	9 of 21 studies showed positive effects on RA: DC management plus follow-up (5), coaching (2) disease mgmt (1), Telehealth (1)	10/21 studies included CGs as secondary recipients of study interventions

AE=adverse events, AMI= acute myocardial infarction, CDP = comprehensive discharge planning, CG = caregiver, DC = discharge, hosp = hospital, ED= emergency department, Med Rec = medication reconciliation, IG = intervention group, PA=Post-acute, RA = readmissions; RCT = randomized controlled trials, RR = Relative Risk, SSD= Statistically significant difference, UC= usual care / control group

Table 1. Literature reviews of hospital discharge interventions in older adults published between 2000-2013

Author(s)/ Year	Aim	Studies	Designs	Subjects	Conclusions	Caregiver Inclusion
Hansen, L. O., Young, R. S., Hinami, K., Leung, A., & Williams, M. V. (2011).	Describe interventions evaluated to reduce hospital RA	43 articles, 12 countries, publ between January 1975 - January 2011 US (28)	RCTs – 16 Quasi-exp+ cohort – 20 Noncontrolled pre-post – 7	Adult med-surg patients Geriatric (9) Heart (11) Lung (5) Veterans (2)	Unable to identify a discrete intervention or bundle of interventions that reliably reduces RA	"Patients and CGs" mentioned in first sentence No specific CG studies referenced
Hesselink, G., Schoonhoven, L., Barach, P., Spijker, A., Gademan, P., Kalkman, C., . . . Wollersheim, H. (2012)	Eval the effects of RCTs aimed to improve handovers between hospital and primary care providers at DC	36 studies, publ between 1990-2011	RCTs	18/36 focused on elderly pts; med-surg, long stay, cancer	Multiple component interventions (34 of 36) Significant positive effect on intervention group (25/36) in one or more outcomes. Most interventions involved facilitating care coordination and communication.	2 studies reported CG strain related to care provision.

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Table 1. Literature reviews of hospital discharge interventions in older adults published between 2000-2013

Author(s)/ Year	Aim	Studies	Designs	Subjects	Conclusions	Caregiver Inclusion
Manderson, B., McMurray, J., Piraino, E., & Stolee, P. (2012)	Describe and eval effects of existing navigator models for	9 studies, publ between 1999-2009 US (6/9) Canada (2/9) Australia (1/9)	RCTs (6 focused specifically on transition from hosp to home)	Chronically ill older adults with multi-morbid conditions	Mixed support for the effectiveness of navigation Roles (2/9 no effect, 1/9 higher ED utilization).	CG outcomes reported in 2 studies: 1 study: guided care increased satisfaction w/ communication 1 study: No difference in CG burden at 1 month
Prvu Bettger, J., Alexander, K. P., Dolor, R. J., Olson, D. M., Kendrick, A. S., Wing, L., . . . Duncan, P. W. (2012).	Identify transitional care strategies that improve outcomes in pts hospitalized w/ AMI, Stroke	62 articles of 44 studies from 13 countries publ between 2000-2012 US (6/44)	RCTs, observational and registry comparisons. Only 8 good quality, 10 studies with low quality rating	Adults over 18 experiencing sudden acute event: AMI or Stroke	Hospital-initiated interventions showed moderate-strength evidence in decreasing hospital LOS for stroke pts and decreasing mortality in MI patients. Insufficient evidence supporting education, community support, and disease management	Review included 5 reports of 4 studies of CG outcomes with education and support interventions All were non-US studies, and 2 of these did not report CG sample size.

AE=adverse events, AMI= acute myocardial infarction, CDP = comprehensive discharge planning, CG = caregiver, DC = discharge, hosp = hospital, ED= emergency department, Med Rec = medication reconciliation, IG = intervention group, PA=Post-acute, RA = readmissions; RCT = randomized controlled trials, RR = Relative Risk, SSD= Statistically significant difference, UC= usual care / control group

Table 1. Literature reviews of hospital discharge interventions in older adults published between 2000-2013

Author(s)/ Year	Aim	Studies	Designs	Subjects	Conclusions	Caregiver Inclusion
Kwan, J. L., Lo, L., Sampson, M., & Shojania, K. G. (2013)	Eval effects of medication reconciliation on post-DC utilization outcomes	20 reports of 18 studies, publ between 1980- July 2012 Canada (5) US (15)	RCTs; pre-post- evals; post-intervention studies	2 studies in pediatric wards, 7 studies on elderly (3) or otherwise high risk (4)	Medication reconciliation alone did not reduce PA utilization, but may if combined with other transitional care interventions	"Patients and CGs" mentioned in introduction No mention of CG involvement in medication reconciliation
Rennke, S., Nguyen, O. K., Shoeb, M. H., Magan, Y., Wachter, R. M., & Ranji, S. R. (2013).	Eval effects of hosp-initiated care transition interventions on pt and utilization	47 studies from 6 countries, publ between 1996-2006 US (24/47)	28 RCTs and 19 controlled trials	Not described	AEs, ED visits, and RA were reported outcomes. Scant evidence to support any one intervention or combination of interventions.	Not mentioned

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six. Parker (2002) noted the difficulty inherent in cross-country comparisons. Two reviews focused on research from the United States (US) only, citing the potentially confounding effect of healthcare system differences (Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011; Popejoy, Moylan, & Galambos, 2009). According to a report by the Organisation for Economic Co-operation and Development (OECD), the US healthcare system is fundamentally different than other industrialized countries as evidenced by low US rankings on population health measures, variations in utilization, and the highest per-capita healthcare spending in the world (OECD, 2014). Further, the hospital to home discharge transition may be very different from country to country. The relationships among patients, family caregivers, and healthcare providers are likely to be culturally-mediated resulting in differing norms and role expectations in different countries. This source of heterogeneity makes it difficult to draw conclusions on the effectiveness of the various discharge interventions.

Another source of heterogeneity is the date range of studies included in these reviews. An integrative review of hospital discharge planning literature from a historical context noted a shift in the literature from descriptive research to intervention studies as hospital care and discharge planning became more complex between 1990 and 2008 (Popejoy et al., 2009). Seven reviews included studies with publication dates prior to 1990 and therefore included studies conducted during years of rapid healthcare system changes in the US in the years following the 1983 Medicare PPS implementation (Hansen, Young, Hinami, Leung, & Williams, 2011; Hyde, Robert, & Sinclair, 2000;

Kansagara et al., 2011; Kwan, Lo, Sampson, & Shojania, 2013; Parker et al., 2002; Phillips et al., 2004; Shepperd et al., 2010). Another review attempted to reduce the heterogeneity of interventions by precisely defining the intervention set and limiting the patient population to older adults hospitalized with heart failure(Phillips et al., 2004). The intervention of interest was comprehensive discharge planning, including an assessment of discharge needs, combined with post-discharge support. This study reported a 25% decrease in relative risk of readmission with a comprehensive combined intervention and further noted that when meta-analytic statistical techniques accounted for heterogeneity, the positive effect of the combined intervention was stable across the included studies (Phillips et al., 2004).

The level of caregiver involvement in the reviews ranged from specific exclusion (Mistiaen, Francke, & Poot, 2007) or not mentioned (Chiu & Newcomer, 2007; Phillips et al., 2004; Rennke et al., 2013) to eleven reviews that included at least one study with some caregiver involvement. The paucity of caregiver-related studies was noted by Parker and colleagues, 2002. When caregivers were mentioned, the level of involvement varied widely as follows: a single social support variable on the presence of a caregiver (Kansagara et al., 2011), a measure of caregiver satisfaction (Hyde et al., 2000; Manderson, McMurray, Piraino, & Stolee, 2012), caregiver problems, burden, or strain related to care provision (Hesselink et al., 2012; Manderson et al., 2012; Mistiaen, Duijnhouwer, & Ettema, 2000; Prvu Bettger et al., 2012), and caregivers as secondary recipients of interventions such as interventions provided to patients and the caregiver if present or caregiver proxies for patients unable to participate (Hesselink et al., 2012; Jacob & Poletick, 2008; Li, Melnyk, & McCann, 2004; Popejoy et al., 2009; Prvu Bettger et al., 2012; Shepperd et al., 2010).

One review focused specifically on interventions provided to caregivers who had an older hospitalized relative (Li, 2004). The focus of this review was care in the hospital and all studies included in the review had a caregiver teaching component aimed at increasing caregiver knowledge and skills. Five of the nine studies tested interventions designed specifically for family caregivers during the transition from hospital to home; of these, four were conducted in the US and involved a comprehensive set of interventions that involved assessment, planning, teaching, and home follow-up (Bull, Hansen, & Gross, 2000c; Lenz & Perkins, 2000; Naylor et al., 1999; Naylor et al., 1994). Lenz and Perkins (2000) found that a 12-week psycho-educational program for the caregivers of heart bypass patients resulting in caregiver reports of more depressive symptoms and complications than the comparison group, possibly because participants may have been more aware of their emotions or felt more comfortable reporting depressive symptoms after receiving the intervention. The other three US studies noted positive effects of transitional care inventions that started in the hospital and continued to the home setting (Bull et al., 2000c; Lenz & Perkins, 2000; Naylor et al., 1999; Naylor et al., 1994). In all four studies caregivers reported needing more information on the expected recovery trajectory, more discharge preparation, and more home support. This caregiver-focused review was the only one of the 20 reviews to note the lack of a theoretical bases for the interventions reviewed (Li, Melnyk, et al., 2004)

Both of the US-only reviews included studies that were focused on patient-caregiver dyads, caregivers as secondary recipients of interventions, or reported a caregiver-focused outcome or intervention (Naylor et al., 2011; Popejoy et al., 2009). Using the lens of US health system reform, Naylor (2011) focused on 9 studies that demonstrated positive effects of transitional care interventions on readmissions. Seven of these studies focused on family caregivers as recipients of interventions. Unfortunately, inconsistent reporting of usual care in the comparison group and the intervention exposure (frequency and duration of services) in the experimental group limited the ability to draw meaningful conclusions.

Healthcare system utilization was the most common outcome measured, either through emergency department visits or hospital readmissions. However some reviewers noted the difficulty in determining whether readmissions were the result of a failure to adequately prepare patients for discharge or the result of illness progression. None of the reviews distinguished between planned and unplanned hospital readmissions. A chronological look at the studies from 2000 to 2013 reveals little improvement in the effectiveness of discharge interventions and little change in family caregiver involvement. The intensity and duration of interventions was not consistently reported. It is possible that combined interventions are more effective simply because of a dose effect; that is, with combined interventions patients and family caregivers have more interaction with healthcare providers and have more opportunity to ask questions specific to their situation. More work needs to be done to understand how patients and family caregivers perceive discharge interventions in order to gain insight into what makes some interventions more effective than others.

The majority of reviews did not offer conclusions on the overall effects of discharge interventions, and the few that did reported issues with research quality and heterogeneity of interventions. Preyde (2009) noted that only 2 of 25 studies had the highest possible quality rating with an average quality rating of 3 on a 0 to 5 scale. Preyde further noted that there was no relationship between quality ratings and effect size, reporting that augmented discharge planning had a large effect (.83) on patient satisfaction, and moderate effects on readmission (.45). Augmented discharge planning was not specifically defined but an examination of the studies cited indicated the interventions were a combination of discharge planning and post-discharge follow-up. This is consistent with the slightly overall positive effect noted for combined face-to-face interventions such as comprehensive discharge planning with post-discharge follow-up (Phillips et al., 2004) and post-discharge disease management follow up by advanced practice nurses (Naylor et al., 2011).

Parker (2002) noted that combined interventions tend to be more effective than any single intervention alone, face-to-face interventions tend to be more effective than phone calls or printed materials, interventions delivered in both the hospital and at home tend to be more effective than interventions in either setting alone, and educational interventions seem to be most effective for patients with conditions that are particularly sensitive to dietary or medication adherence such as diabetes and heart failure. Several reviewers noted that effect sizes could not be calculated because standard deviations were not consistently reported.

In answer to the first research question, the involvement of caregivers in these reviews ranged from one review that focused on family caregivers of hospitalized patients exclusively (Li, Melnyk, et al., 2004) to the opposite end of the spectrum with another review that excluded family caregiver studies specifically (Mistiaen et al., 2007). Caregivers had little to no involvement in seven studies. Three of these did not mention family caregivers at all (Chiu & Newcomer, 2007; Phillips et al., 2004; Rennke et al., 2013) and another four mentioned family caregivers in the text but no studies including caregivers were included in the review (Bauer et al., 2009; Hansen et al., 2011; Kwan et al., 2013; Preyde, Macaulay, & Dingwall, 2009). Eleven reviews included at least one study that involved family caregivers, typically a discharge intervention provided to a patient-caregiver dyad (Hesselink et al., 2012; Hyde et al., 2000; Jacob & Poletick, 2008; Kansagara et al., 2011; Manderson et al., 2012; Mistiaen et al., 2000; Naylor et al., 2011; Parker et al., 2002; Popejoy et al., 2009; Prvu Bettger et al., 2012; Shepperd et al., 2010).

According to transitions theory, nursing therapeutics involves engaging with patients and caregivers, communicating situation-specific information, and providing opportunities for role learning and role rehearsal through which patients and caregivers can achieve role mastery (Meleis et al., 2000). The transition time span was evident in these reviews as patients and caregivers interact with different providers over time as discharge interventions are provided by hospital staff prior to discharge and then by community healthcare providers after discharge. Some interventions tested continuity of providers throughout the transition process (Hansen et al., 2011). Rennke, et al. (2013) noted in a review of hospital discharge safety interventions that none of the studies addressed the contextual factors that may influence the effectiveness of a transitional care intervention, an area worthy of further exploration. In terms of nursing therapeutics, Naylor (2011) stressed the importance of individually tailored interventions including comprehensive discharge planning, care coordination and post-discharge support. This is congruent with the hospital discharge transition model which is based on the interactions between patients, family caregivers, and healthcare providers. Therapeutic interventions are provided that address personal and situational conditions in order to positively influence the hospital discharge transition process and patient and caregiver outcomes.

These literature reviews provide an overview of the extensive body of research on hospital discharge interventions. The results of most interventional studies were not definitive and few found significant differences between intervention and comparison groups. The mixed results were attributed to differences in the interventions, lack of rigor in study designs (e.g., small samples), lack of clarity on what constituted usual care for the comparison group, and lack of reporting the information necessary to calculate effects.

Next, an exploration of the qualitative and non-experimental quantitative literature guided by this model is the focus of the second and third research questions to understand the concepts and variables of interest in studies of caregivers during seniors' hospital discharge transitions.

QUALITATIVE RESEARCH

Ten qualitative studies meeting the original inclusion criteria were identified. One study included an adolescent in the sample, but the decision was made to include this study because the rest of the subjects were seniors and the only difference noted in the article was that two caregivers (both parents) were interviewed (McLane, Jones, Lydiatt, Lydiatt, & Richards, 2003). Transitions have been described as the complex process involving a human response to a time of change (Kralik, Visentin, & van Loon, 2006). Facilitating transitions has been described as a key element of nursing practice (Meleis & Trangenstein, 1994) and a central concept in nursing (Meleis et al., 2000). In order to answer research question two, these 10 qualitative studies were evaluated using a transitions theory perspective and are summarized in Table 2. The nature of transitions includes the type and patterns of transition. In this review, the type of transition described is the discharge from hospital to home, which represents both a situational transition from an acute care hospital to the home setting and an illness-wellness transition from an acute illness requiring hospitalization to the return to a state of health in which the patient is able to return home even if not yet fully recovered. Components of transitions theory are evident in each of these studies. The information gleaned from these studies informed

Table 2. Summary of qualitative studies of hospital discharge experiences with Transitions theory concepts

Author(s) / Year / Design	Aim / Theory	Participants	Findings	Transition Concepts
Benzar, E., Hansen, L., Kneitel, A. W., & Fromme, E. K. (2011) Qualitative descriptive	Describe experiences of family caregivers receiving PC consults to identify how PC teams can best prepare pts and caregivers for the post-hospital experience	19 interviews (mean age =66) 11/19 female (58%) 11 in person 8 by phone 15 w/ CGs 1 w/ patient 3 w/ both	Three themes identified that PC team could address prior to DC: 1. Prognosis – vague, overly optimistic, and lacked information about what to expect. 2. Symptom management: lacked sufficient information about how to recognize and manage symptoms. 3. Contact for questions: Needed help navigating healthcare system.	**Properties:** Awareness **Conditions:** Preparation & Knowledge **Therapeutics:** Education, Communication **Responses:** Feeling connected; Interaction; Developing confidence & coping
Coughlin, C. (2012) Ethnography	Describe nurses' and pts' perceptions of care during main events of care delivery (times of significant interaction) such as admission, transfer to surgery, and DC Theory: Caring Science and Caring Theory (Watson, 1988)	10 patients observed (ages 57-88), 9/10 white, 9/10 male 2 nurses observed and interviewed	Two major findings: 1. The patient and the nurse had different perceptions of the care experience 2. The presence of family or a support person influenced the patient's perception of care.	**Properties:** Critical points and events (times of increased interactions during DC prep) **Conditions:** Preparation & Knowledge **Therapeutics:** DC preparation **Responses:** Feeling connected; Interaction; Developing confidence & coping

CG = caregiver , DC = discharge, HH=home health, PC= palliative care, Pt = patient , VA= Department of Veterans Affairs

Table 2. Summary of qualitative studies of hospital discharge experiences with Transitions theory concepts

Author(s) / Year / Design	Aim / Theory	Participants	Findings	Transition Concepts
Dossa, A., Bokhour, B., & Hoenig, H. (2012) Qualitative longitudinal	Describe pt and CG experiences with transitions home following hospital discharge and identify care breakdowns related to rehabilitation	18 interviews 9 male Caucasian VA pts, age 70-88, w/ mobility impairments 9 female CGs, 4 spouses, 3 daughters, 2 significant others	Four domains of communication breakdown impacted continuity of care and recovery: 1. Poor communication between pts and providers regarding care at home 2. Whom to contact post DC 3. Provider response to phone calls following DC 4. Provider-provider communication	**Properties:** Time span (interviews at 2 wks, 1 mo., 2 months post-DC) **Conditions:** Preparation & Knowledge **Therapeutics:** Communication; Care coordination **Responses:** Feeling connected; Interaction (who to call w/ post DC problems)
Foust, J. B., Vuckovic, N., & Henriquez, E. (2012) Qualitative descriptive	Describe the hospital-to-HH transition from the perspectives of pts, CGs, and home health clinicians	40 pts, 29 female 35 informal caregivers, 12 spouses, 9 adult children 15 clinicians – 6 nurses and 9 physical therapists	CGs and clinicians emphasized inadequate preparation of CGs during the discharge process; pts more aware of DC date than caregivers; pts w/ planned surgeries more likely to know what to expect. Most satisfied w/ DC instructions or had no suggestions. CGs described a "peripheral status" and frustration in getting information; pt-centered but not family-centered process	**Properties:** Awareness (of DC date); time span (1st interview w/in 45 days of DC / HH admission, 2nd two weeks later) **Conditions:** Preparation & Knowledge **Responses:** Interacting; Developing confidence and coping

CG = caregiver , DC = discharge, HH=home health, PC= palliative care, Pt = patient , VA= Department of Veterans Affairs

Table 2. Summary of qualitative studies of hospital discharge experiences with Transitions theory concepts

Author(s) / Year / Design	Aim / Theory	Participants	Findings	Transition Concepts
Graham, C. L., Ivey, S. L., & Neuhauser, L. (2009) Qualitative thematic analysis of focus group data and 5 longitudinal case study analyses	Assessed the needs of pts and CGs during the transition from hospital to home. Theory: Social ecological model of health behavior (McLeroy, Bibeau, Steckler, &Glanz, 1988)	20 focus groups with 159 CGs who recently assisted a care recipient after hospital DC. 8 cultural / ethnic groups represented	Themes: • Inadequate caregiver training • Inadequate info from hospital DC planner • Inadequate informal support • Cultural and financial barriers to using long-term care services	**Conditions:** Preparation & Knowledge; cultural beliefs and attitudes, socioeconomic factors, community & societal factors (resources) **Therapeutics:** Education and Information **Responses:** Feeling connected; interacting
Magilvy, J. K., & Congdon, J. G. (2000) Ethnography	Examined the experience of transitioning across health care services for rural elders and their families noting which aspects were most problematic and what interventions, individual supports and community resources are needed	175 people in 13 counties in rural Colorado. 49 older adults including pts, caregivers, and community residents 113 healthcare providers 13 community leaders	Theme: the crisis nature of healthcare transitions for rural older adults and their families. Crises were made worse by: Surprise, limited knowledge, inconsistent discharge planning, changing family support, and poor continuity of care. Home health services were a strength	**Properties:** Awareness; Critical points / events **Conditions:** Preparation & Knowledge; community, CG support **Therapeutics:** DC planning, Home health services **Responses:** Feeling connected (continuity); Location and Being situated (distant caregivers, times of crisis)

CG = caregiver , DC = discharge, HH=home health, PC= palliative care, Pt = patient , VA= Department of Veterans Affairs

Table 2. Summary of qualitative studies of hospital discharge experiences with Transitions theory concepts

Author(s) / Year / Design	Aim / Theory	Participants	Findings	Transition Concepts
McLane, L., Jones, K., Lydiatt, W., Lydiatt, D., & Richards, A. (2003) Grounded theory	Evaluate a “cooperative care” program on patients with head and neck cancer. Cooperative care program based on Orem’s Self Care Deficit Theory (1991)	21 participants Patients Caregivers Providers	Pts and caregivers perceived cooperative care as an experience that took away their fear by providing self-care education within a caring community. Home-like setting allowed for supported practice of needed skills.	**Properties:** Engagement; Change and difference **Conditions:** Personal characteristics (coping style), meaning, Preparation & Knowledge; CG support; “caring community” **Therapeutics:** Pt / CG education and support in a homelike setting. **Responses:** Feeling connected, interacting, developing confidence and coping; mastery
Naylor, M. D., Stephens, C., Bowles, K. H., & Bixby, M. B. (2005) Qualitative descriptive .	Identify the needs of cognitively impaired older adults during and after hospitalization and differences between pt and CG needs	51/158 pts screened in for cognitive impairment Interviews: 5 patients (mean age 80.2) 5 CGs	3 categories of concern: • Managing and negotiating care with multiple providers • Managing illness • Psychosocial support and coping	**Properties:** Engagement, Change and difference, time span (interviews: in hospital, 48 hrs, 2 wks, 6 wks post-DC) **Conditions:** Preparation & Knowledge **Responses:** Feeling connected (CG social isolation was a consistent theme)

CG = caregiver , DC = discharge, HH=home health, PC= palliative care, Pt = patient , VA= Department of Veterans Affairs

Table 2. Summary of qualitative studies of hospital discharge experiences with Transitions theory concepts

Author(s) / Year / Design	Aim / Theory	Participants	Findings	Transition Concepts
Parry, C., Kramer, H. M., & Coleman, E. A. (2006) Qualitative descriptive	Explore the pt experience of receiving a pt-centered coaching intervention. Content analysis	32 patients participated in semi-structured interviews. 8 caregivers accompanied patient to interview.	3 positive themes identified related to receiving the pt-centered intervention: • Continuity through the transition • Self mgmt knowledge • Coaching relationships	**Properties:** Engagement **Conditions:** Preparation & Knowledge **Therapeutics:** Care Transitions Intervention – four pillars: 1) Med self-mgmt 2) Pt-centered record 3) Follow up w/ providers 4) Knowledge/ self-mgmt **Responses:** Interacting, Mastery

CG = caregiver , DC = discharge, HH=home health, PC= palliative care, Pt = patient , VA= Department of Veterans Affairs

Table 2. Summary of qualitative studies of hospital discharge experiences with Transitions theory concepts

Author(s) / Year / Design	Aim / Theory	Participants	Findings	Transition Concepts
Popejoy, L. L. (2011). Qualitative descriptive	Explore decisions made by hospitalized older adults, families, and health care team members about hospital DC Theory: Decision science (Baron, 2000)	Older adults (n = 13, mean age 84) Family members (n = 12, mean age 71) Health care team members nurse discharge planners and social workers (n = 7, mean age 47)	5 themes: • Home as the destination • Staying as independent / adjusting • Advocacy and vigilance • Deciding what to tell (family) • Changing the plan	**Properties:** Change and difference (changing health care needs) **Conditions:** Beliefs and attitudes (independence, preference to return home); Preparation and knowledge; CG characteristics – ability to provide care **Therapeutics** • Communication • Needs assessment • DC planning • Care coordination • Explaining options • Decision-making support **Responses:** Interacting, Location and Being Situated (at home), Mastery

CG = caregiver , DC = discharge, HH=home health, PC= palliative care, Pt = patient , VA= Department of Veterans Affairs

development of the coding procedures for data extraction in the final phase of this literature review. The essential properties of transitions, the transition conditions that facilitate or inhibit transition processes, therapeutics, and patterns of response are noted for each study in Table 2.

Transition Properties

Five interconnected properties of the transition process have been identified: awareness, engagement, change and difference, time span, and critical points and events. Awareness of the discharge date is important for a smooth hospital discharge transition and was noted as an important theme in two studies (Foust et al., 2012; Magilvy & Congdon, 2000). Most patients (75%) knew of their impending discharge at least one day in advance but caregivers reported having difficulty obtaining information from hospital staff and some reported learning about the discharge after the patient was already home (Foust et al., 2012). This caused caregivers to be upset and left little time to prepare for a safe, smooth transition. Patients undergoing a planned surgery were more aware of what to expect and how long they would most likely be in the hospital (Foust et al., 2012). An ethnographic study of health care transitions of seniors living in rural areas described the lack of awareness of community resources (Magilvy & Congdon, 2000. Seniors typically waited to access health care services until the situation was critical because they were not aware of possible options, which left providers with no opportunity for early intervention to prevent hospital readmission. Further, hospital discharge planning was described as "hasty" and discharge decisions were often made quickly which resulted in confusion and crisis (Magilvy & Congdon, 2000).

Engagement of patients and caregivers was evident in many studies and took a variety of forms. Engagement of patients as partners in care was the focus of a study evaluating a cooperative care program for patients with head and neck cancer (McLane et al., 2003). In this study the concept of engagement was further extended to the relationship of the attending and resident physicians in discussions on understanding the needs of patient and caregivers and building trusting relationships (McLane et al., 2003). A qualitative study of a transition coaching model emphasized the importance of patient-centered education and patient "activation" in which patients take an active role in managing their health care versus passive interactions with healthcare providers. Activated informed patients have the skills and knowledge to manage their health care for the best possible outcomes (Parry, Kramer, & Coleman, 2006).

Change and difference are essential properties of hospital discharge transitions because changing healthcare needs require different caregiver strategies. This was particularly evident in a study of cognitively impaired seniors (Naylor et al., 2005). Caregivers described additional responsibilities as care became more complicated and the patient's behavioral symptoms worsened. Patients and caregivers had difficulty coping with changes and loss of strength, function and autonomy and became more dependent on caregivers (Naylor et al., 2005). In patients with head and neck cancer, change and difference was related to disfigurement and dysfunction that required new skills to manage wounds and strategies to maintain adequate nutrition (McLane et al., 2003). Changes in physical health are closely tied with decisions on post-hospital care. Popejoy (2011) used decision-science as a conceptual framework to explore discharge plans in older adults. Changes in health status required adjustments in order to maintain independence with the goal to return home if possible. Changing the discharge plan was a common theme that was also interrelated with personal characteristics, especially related to beliefs and attitudes about independence (Popejoy, 2011).

Transitions occur over time and the transition property of time span was noted as an element of study design in three studies that employed sequential interviews (Dossa et al., 2012). To explore changes in the transition process over time for seniors with cognitive impairment, patients and caregivers were interviewed at four time points: prior to hospital discharge, within 48 hours of discharge, at two weeks and six weeks after discharge (Naylor et al., 2005). Caregivers struggled to accept changes in the patient's condition throughout all time points. Early in the transition process, caregivers were concerned with practical needs such as transportation and ensuring patient's basic care needs were met. As time passed, caregivers were more concerned with care coordination and managing changes in the patient's condition. At six weeks caregivers were mainly concerned with patient behavioral issues and symptom management (Naylor et al., 2005). A study of post-discharge therapy problems with interviews conducted at two weeks, one month, and two months noted communication breakdowns throughout the transition time span with one participant noting that changes in staff each week led to discontinuity of care (Dossa et al., 2012). A study of hospital to home discharges with home health services support started with interviews at two time points with the first within 45 days of discharge and the second two weeks later but the researchers changed the study protocol to a single interview after determining that the second interviews were not contributing new data (Foust et al., 2012).

Critical points and events were key features of two ethnographic studies. Coughlin (2012) studied main events during hospitalization and noted increased interactions among patients, caregivers, and healthcare providers during discharge preparations. Communication during interactions may be verbal or non-verbal and contribute to the development of a therapeutic relationship. Patient and caregiver perceptions of these interactions, whether complaints or high levels of satisfaction, were often centered on one memorable event such as providing reassurance and thorough explanations (Coughlin, 2012). A study of rural elders revealed a major theme of the crisis nature of transitions which were characterized by surprise and disruption (Magilvy & Congdon, 2000).

Transition Conditions

The processes and outcomes of transitions are facilitated or inhibited by personal and environmental conditions. Personal conditions that influence healthy transitions include characteristics such as cognitive impairment which makes transitions more complicated (Naylor et al., 2005), personality and coping style (McLane et al., 2003), socioeconomic status, literacy, and cultural beliefs and attitudes (Graham, Ivey, &

Neuhauser, 2009) and personal meanings such as independence and autonomy in healthcare decision-making (Popejoy, 2011). Family caregiver availability is an transition condition that was particularly important in a study of rural elders because many adult children move to urban areas for employment opportunities and live some distance from rural elders (Coughlin, 2012). The ability to meet the physical demands of caregiving was a prominent feature of a study of elderly spousal caregivers (Popejoy, 2011). Transition conditions also include caregiver preparation and knowledge. For example, a grounded theory study of patients with head and neck cancer revealed that cooperative care reduced fear by increasing preparation and knowledge through self-care education in a home-like environment (McLane et al., 2003). For patients with head and neck cancer, personal meanings are associated with disfigurement, physical dysfunction and care needs. Positive relationships with the caregiver, called a care partner, and the healthcare providers facilitated autonomy and dignity as patients and caregivers developed the confidence and coping skills to master self-care (McLane et al., 2003).

Preparation and knowledge were the most common personal factors described in the qualitative research. This is expected because most discharge interventions include an educational component focused specifically on preparing patients and caregivers for discharge. For older adults receiving palliative care consults, preparation and knowledge included knowing what to expect, how to manage symptoms and how to navigate the healthcare system (Benzar, Hansen, Kneitel, & Fromme, 2011). Knowing who to contact with questions or concerns is also important to help patients and caregivers feel connected to the healthcare team and feel confident in their ability to manage care at home (Dossa et al., 2012). Self-management knowledge, including signs to watch for and report, helped patients and caregivers achieve mastery of the health condition as the patient and caregiver become “activated” and informed consumers of healthcare services (Parry et al., 2006). Inadequate information from discharge planners and insufficient caregiver training make transitions more difficult for patients and caregivers (Graham et al., 2009). Patients and caregivers report unmet information needs when the information provided is too general and not individualized to the patient’s specific needs.

Community and societal factors include availability of resources for persons of low socioeconomic means or with limited English proficiency (Graham et al., 2009) and access to resources for those living in rural areas (Magilvy & Congdon, 2000). Discharge decision-making is influenced in part by societal factors such as Medicare benefits for post-acute services and caregiving options for patients who are able to return home (Popejoy, 2011). Community and societal factors influence patient and caregiver personal factors to either facilitate or inhibit hospital discharge transitions.

Nursing Therapeutics

The 10 qualitative studies explored patient and caregiver experiences and perceptions in which descriptions of the interventions provided during the hospital discharge transition process were elicited during interviews or focus groups. The therapeutic interventions described were varied and included discharge decision-making support (Popejoy, 2011), discharge planning (Magilvy & Congdon, 2000; Popejoy, 2011), communication of information and education (Benzar et al., 2011; Dossa et al., 2012; Foust et al., 2012; Graham et al., 2009), care coordination (Dossa et al., 2012; Popejoy, 2011), emotional support (McLane et al., 2003), and arranging for post-acute services such as home health (Magilvy & Congdon, 2000). One study described patient experiences of a combined intervention that included education on medication self-management, a patient-centered medical record, education on red flag symptoms to watch for and report, and follow-up with providers and contact information to call if a problem arises (Parry et al., 2006). These discharge interventions were provided during interactions with patients and caregivers and were designed to increase preparation and knowledge of patients and caregivers to increase confidence, coping, and mastery of managing new or changed healthcare needs.

Patterns of Response

Healthy transitions are characterized by process indicators which reflect how the transition is going as the transition process unfolds and outcome indicators which are the end result of the transition process (Meleis, 2010). Process indicators described by transitions theory include feeling connected, interacting, location and being situated, and developing confidence and coping. Outcome indicators include mastery of the skills needed to manage the transition and the development of fluid integrative identity as the person is changed by the transition experience.

Process Indicators

Developing confidence and coping was a common outcome in several of the qualitative studies as caregivers described learning how to manage after hospital discharge (Benzar et al., 2011; Coughlin, 2012; Foust et al., 2012; McLane et al., 2003). Perceptions of care continuity are related to feeling connected to healthcare providers. Family caregivers want to know who to call if they have problems or questions because hospital staff are most familiar with the patient's recent health issue and community healthcare providers may be less knowledgeable if they have not received information about the patient's hospital stay (Dossa et al., 2012). Difficult transition situations may be characterized by feeling of disconnection and lack of support. Social isolation was a consistent theme for caregivers of seniors with cognitive impairment (Naylor et al., 2005).

Feeling connected is closely related to the process indicator of interacting. According to Meleis (2000), it is through interacting that the caregiving relationship is developed, clarified, and understood. Interacting with healthcare providers was an important element in developing a "community of caring" for patients and caregivers in a cooperative care program for head and neck cancer (McLane et al., 2003). Interacting was a recurring theme in several studies as patients, caregivers, and healthcare providers interacted during discharge planning, preparation, and post-acute support (Benzar et al., 2011; Coughlin, 2012; Graham et al., 2009; Parry et al., 2006; Popejoy, 2011). Location and being situated were particularly important to seniors who strongly preferred being at home after hospital discharge to rehabilitation and other post-discharge alternative care settings (Popejoy, 2011). Location and being situated were key elements of the transition experience in a study of rural-dwelling seniors with distant caregivers (Magilvy & Congdon, 2000).

Outcome Indicators

Two outcome indicators of a healthy transition process are mastery of the needed skills to manage the transition and developing a new identity as the person is transformed by the transition process. The outcome of mastery is the end-result of processes that encourage the development of confidence and coping (Meleis et al., 2000). These indicators were evident in two of the ten qualitative studies reviewed (Parry et al., 2006). The care transition intervention was based on a patient-centered coaching model specifically designed to equip and activate patients and caregivers to master self-care throughout a hospital to home transition (Parry et al., 2006). In an evaluation of a cooperative care program, patients with head and neck cancer and their caregivers had the opportunity to achieve mastery in a safe supportive environment (McLane et al., 2003). Transitions theory concept of fluid integrative identity figured prominently in this study as patients and caregivers adapted to the dysfunction and disfigurement associated with head and neck cancer (McLane et al., 2003).

Research question two focused on the nature of qualitative literature of hospital discharge transitions using the lens of transitions theory. These qualitative studies illustrate how transition concepts are interrelated, the ways in which patient and caregiver responses are influenced by interactions with healthcare providers during discharge interventions, and the transition conditions that facilitate or inhibit smooth transitions. Personal transition conditions may be assessed for and incorporated into discharge planning, thereby tailoring discharge interventions to the unique needs and circumstances of the senior and family caregiver. In these studies, transition time span was incorporated into research designs through sequential interview schedules. Much of the qualitative research focused on the interactions and relationships among hospitalized seniors, family caregivers, and healthcare providers. Engagement of patients and caregivers occurred during discharge interventions that involved communication such as patient self-management education or discharge instructions. These discharge interventions were mostly aimed at increasing patient and caregiver preparation and knowledge. During the hospital discharge process, positive productive interactions led to the development of confidence and coping in patients and families. The qualitative findings are summarized in Table 2 and informed the development of the code sheet and code book for the final phase of the review.

QUANTITATIVE NON-EXPERIMENTAL RESEARCH

Research question three examines the theoretical underpinnings and variables of interest in non-experimental quantitative research of hospital-to-home discharge transitions of seniors and their caregivers. Seven non-experimental quantitative studies identified in the literature review explored the relationships among discharge transition variables such as satisfaction and feelings of preparedness or readiness for discharge and are summarized in Table 3.

Theoretical frameworks

All seven studies described a theoretical basis that guided the study design and exploration of the relationships between the variables of interest. These studies are summarized in Table 3. Three studies relied on the stress theories of Lazarus and Folkman (1980, 1984) and focused on coping (Huber & McClelland, 2003), appraisal (Karen A. Schwarz & Dunphy, 2003), and learning processes (Silver, Wellman, Galindo-Ciocon, & Johnson, 2004). Two studies by Bull (2000a, 2000b) used the Donabedian (1966) structure, process, outcome framework. Task-specific theory was used to examine the effect of service use on readmissions (Li, Morrow-Howell, & Proctor, 2004). Stressors and the person's response to stressors according to Neuman's System Model (Neuman, 1995) informed a study of caregiver support on hospital readmissions for older adults (Schwarz, 2000).

Transition Variables

Transition conditions influence both the transition process itself and patterns of response. The transition condition variables and instruments used in these studies are listed in Table 3. Transition conditions measured in these studies included patient characteristics such as severity of heart failure (Li, Morrow-Howell, et al., 2004) and functional status (Bull et al., 2000a, 2000b), and caregiver characteristics such as

Table 3. Non-experimental quantitative hospital discharge research with caregivers of seniors, 2000-2013.

1st Author, Year	Study / Sample Description	Theory / Framework	Variables / Instruments	Findings	Comments
Bull, M. J., Hansen, H. E., & Gross, C. R. (2000a)	Hierarchical regression model predicting elder and family satisfaction with DC planning. 134 dyads; pts aged 55-94, mean 72.9 (8.8) yrs; CG's mean age 59.3), 73.3% female, 54.8% spouses, 40.4% adult children	Structure, Process, Outcome (Donabedian, 1966)	• Modified Client Satisfaction Questionnaire – 8 items • Continuity of care – 12 items • Preparedness – 1 rating, 0-10 • SF-36 • Internal subscale Health Locus of Control – 6 items • Perception of difficulty managing care – 13 items	Model explained 46% of the variance in pt satisfaction and 49% of variance in CG satisfaction. CG perceptions of care continuity and preparedness explained 35.6% of variance in CG satisfaction. Length of time in the CG role was inversely related to satisfaction.	Data collected prior to discharge and by phone survey 2 wks after DC. Satisfaction for pts and CGs, feelings of preparedness, and continuity can be influenced by nursing interventions.
Bull, M. J., Hansen, H. E., & Gross, C. R. (2000b)	Compare family caregiver outcomes by level of involvement in discharge planning for elderly patients with HF. 130 family CGs	Structure, Process, Outcome (Donabedian, 1966)	• Modified Client Satisfaction Questionnaire – 8 items • Continuity of care – 12 items • Preparedness – 1 rating, 0-10 • SF-36 • Internal subscale Health Locus of Control – 6 items • Perception of difficulty managing care – 13 items • Single item re: extent to which they were involved in DC planning: "Not at all," "a little," "moderately," "a great deal."	26.2% of caregivers reported no involvement in DC planning. 32.3% reported a lot of involvement CGs with greater involvement had significantly higher perceptions of continuity, role acceptance, feelings of preparedness, and satisfaction at 2 wks. At 2 months, continuity of explanations, role acceptance, and Vitality (SF-36) were sig. higher.	Distinguished between participation (healthcare perspective) and involvement (consumer perspective.)

ADL = Activities of daily living, APN=Advanced practice nurse, CG=Caregiver, DC = Discharge, ED=emergency department, HF= heart failure, IADL = Instrumental activities of daily living, RA =readmission, RR = Relative risk

Table 3. Non-experimental quantitative hospital discharge research with caregivers of seniors, 2000-2013.

1st Author, Year	Study / Sample Description	Theory / Framework	Variables / Instruments	Findings	Comments
Hendrix, C., Tepfer, S., Forest, S., Ziegler, K., Fox, V., Stein, J., . . . Colon-Emeric, C. (2013)	Describe a clinical demonstration program, Transitional Care Partners (TLC) to support DC transitions in veterans age 60+ and their CGs. 47 veterans, 83% 65+ 33 had caregivers at home, 15 caregivers completed scales.	Program description based on Naylor's Transitional Care Model and included hospital visit by APN and home follow up	• Preparedness in Caregiving • Short Zarit Burden Scale	Mean preparedness and burden scores before and after the program were unchanged. Pts in the program had fewer ED visits and fewer RAs at 30 and 60 days after DC. (Only veterans' hospital ER and RAs were measured, pts may have accessed care at community hospitals.)	Anecdotes from pt and CGs reported it was "reassuring to have ready access to someone who can help when issues or problems arise" and was convenient to have home support instead of going back and forth to the veterans' hospital and clinics for healthcare.
Huber, D. L., & McClelland, E. (2003)	Descriptive pilot to investigate patient and CG participation, preferences, and desire for information in DC planning n=62, 37 male, 25 female, mean age 74.3 (8.4)	Stress, coping, and information needs for decision-making (Folkman & Lazarus, 1980).	• Patient Participation Preferences Assessment (PPPA) • Family Preferences Assessment (FPA) • Living with Heart Failure (LHF) OR Diabetes Quality of Life Survey (DQOLS) • Patient Opinion of Nursing Care (PONC)	The PPPA is a useful, valid, and reliable instrument and nurses can use it with the FPA for comprehensive DC planning. Need to explore patient and CG views on discharge planning and factors that contribute to rehospitalization.	Low correlation (0.25) between PPPA and FPA indicating low level of agreement between pt and family CG preferences for DC planning.

ADL = Activities of daily living, APN=Advanced practice nurse, CG=Caregiver, DC = Discharge, ED=emergency department, HF= heart failure, IADL = Instrumental activities of daily living, RA =readmission, RR = Relative risk

Table 3. Non-experimental quantitative hospital discharge research with caregivers of seniors, 2000-2013.

1st Author, Year	Study / Sample Description	Theory / Framework	Variables / Instruments	Findings	Comments
Li, H., Morrow-Howell, N., & Proctor, E. K. (2004)	Examine the effects of informal and formal service use on hospital RA of HF pts. n=192 Age mean 77.5 (7.1), range 65-98 years	Task-specific theory (Litwak,1985)	• Informal service use – assistance by unpaid CGs • Formal service use – paid CGs • HF duration - time since diagnosis • Severity of illness - NYHA Classification • Functional status – level of dependency (0-2 scale) for 7 ADLs and 6 IADLs • Compliance – 2 items (yes/no) • CG limitations – 5 items (yes/no)	35% of pts had at least one RA between 2 and 14 weeks after hospital DC. 55% of participants had lower SES and less than HS education 45% had Class III or IV heart failure Only 2 factors in the model were sig. predictors of RA: • Length of HF history: RR=1.11 • Medication compliance: RR=0.53	Secondary analysis, measures may not have been sensitive enough to significantly influence model.
Schwarz (2000)	Examine the influence of CG and support variables on RA 60 CGs aged 27-92, mean age 64.4(14.3), 73% female, 60% spouses, 30% adult children	Neuman's Systems Model (Neuman, 1995)	• Perceived physical health of care recipient– 1 item • Number of home health care services used • Modified Inventory of Socially Supportive Behaviors – 40 items summarized in 5 subscales • Satisfaction with Informal Socials Support - 4 items • Center for Epidemiological Studies Depression Scale – 20 items	33% of care recipients readmitted within 3 months At 3 months, RA was associated with depressive symptoms (*r*=.24), lower tangible support (*r*=-.24), and lower emotional support (*r*=-25) The multivariate regression model to evaluate the effects of CG support, satisfaction, and depressive symptoms on RA was not significant.	73% received home health services. R^2 increased by 0.01 when home health service utilization was added to the model.

ADL = Activities of daily living, APN=Advanced practice nurse, CG=Caregiver, DC = Discharge, ED=emergency department, HF= heart failure, IADL = Instrumental activities of daily living, RA =readmission, RR = Relative risk

Table 3. Non-experimental quantitative hospital discharge research with caregivers of seniors, 2000-2013.

1st Author, Year	Study / Sample Description	Theory / Framework	Variables / Instruments	Findings	Comments
Schwarz, K. A., & Dunphy, G. (2003)	Perceived stress in family caregivers of older adults with HF after hospital DC 75 CGs, mean age 63 (15.5), 73.3% female, 51% spouses, 37% adult children	Stress appraisal (Lazarus & Folkman, 1984)	• Perceived physical health of care recipient – 1 item • Perceived Stress Scale – 14 items • Salivary cortisol • Center for Epidemiological Studies Depression Scale – 20 items • Modified Inventory of Socially Supportive Behaviors – 40 items summarized in 5 subscales	The model to evaluate whether informal social support moderates negative effects of stress on depressive symptoms was not significant. CG's with higher perceived stress did not have higher cortisol levels than CGs with less perceived stress. Perceived stress sig. related to depressive symptoms (*r*=.7, p=.01)	Psychometric evaluation of the Perceived Stress Scale indicated the 14 items are related and not redundant. Global measures of perceived stress over time may not reflect current stress as measured by salivary cortisol.

ADL = Activities of daily living, APN=Advanced practice nurse, CG=Caregiver, DC = Discharge, ED=emergency department, HF= heart failure, IADL = Instrumental activities of daily living, RA =readmission, RR = Relative risk

Table 3. Non-experimental quantitative hospital discharge research with caregivers of seniors, 2000-2013.

1st Author, Year	Study / Sample Description	Theory / Framework	Variables / Instruments	Findings	Comments
Silver, H. J., Wellman, N. S., Galindo-Ciocon, D., & Johnson, P. (2004)	Descriptive correlation study of needs and preparedness of family CGs of seniors w/ enteral feedings 30 pt-CG dyads 14 /30 spouses 11/30 adult children	Technology-dependent caregiving stress- process theory (Lazarus & Folkman, 1984; Pearlin et al. 1990; Smith, 1994).	• Home Enteral Nutrition Caregiver Tasks Checklist – 33 items • Caregiver daily hours of care • Descriptive items: who provided training, where and when • Medical diagnoses, type of feeding and schedule • Preparedness for Caregiving Scale • Skaff Caregiver Competence Scale • Effectiveness as Caregivers – 1 item self-rated.	1/3 of CGs helped w/ ADLs; all CGs helped w/ IADLs; provided an average of 22/33 tasks on the checklist 21/30 received training from nurses 15/30 were trained at the hospital prior to DC; 9 trained at home; 4 trained in a clinic, 2 received no training Caregivers tasks performed - average 19.7 (8.1) total; Hispanics 25 (4.4), white 16.6(8.2) Tasks needed training 17.9 (5.4) Tasks received training 6.3 (6.04) More tasks associated with higher overload (*r*=.48, *p*=.01) and higher caregiving hours (*r*=.58, *p*=.001)	Low level of patient involvement in managing home enteral nutrition High % of unmet training needs and low overall preparedness. CGs providing the most tasks were the least prepared w/ lowest competence scores. Most common reason to refuse study participation was "feeling extremely overwhelmed."

ADL = Activities of daily living, APN=Advanced practice nurse, CG=Caregiver, DC = Discharge, ED=emergency department, HF= heart failure, IADL = Instrumental activities of daily living, RA =readmission, RR = Relative risk

preferences for involvement (Huber & McClelland, 2003) and internal locus of control (Bull et al., 2000a, 2000b). Transition response variables included indicators such as satisfaction with healthcare provider interactions (Bull et al., 2000b; Huber & McClelland, 2003), developing confidence and coping as measured by feelings of preparedness (Bull et al., 2000a), and mastery as measured by self-ratings of caregiver effectiveness (Silver et al., 2004). Feelings of continuity and preparedness were significant predictors of caregiver satisfaction (Bull et al., 2000b). In a study of seniors receiving home enteral nutrition, caregivers reported multiple unmet training needs and overall low feelings of preparedness for the caregiving role in providing technology-dependent care (Silver et al., 2004). Greater involvement in the discharge process led to higher perceptions of continuity, feelings of preparedness, role acceptance and satisfaction at two weeks (Bull et al., 2000a). This study made a clear distinction between the concepts of caregiver participation and caregiver involvement (Bull et al., 2000a). From the healthcare provider perspective, seniors and family caregivers may participate in the discharge process but the process is ultimately controlled by and the responsibility of healthcare providers. From the consumer perspective, involvement is a broader concept of engagement. The hospital discharge transition process is characterized by interactions with healthcare providers in which hospital discharge interventions are provided. These interventions address specific transition conditions and result in increased feelings of connectedness, confidence, and coping.

Utilization measures such as hospital readmissions or emergency room visits are a common outcome measure in studies of discharge transitions. Unplanned healthcare utilization is presumed to be avoidable if it occurs soon after hospital discharge (Jencks et al., 2009). This assumption is based on the idea that the needed for unplanned care may be the result of discharging patients before they are stable or a failure to adequately prepare patients and caregivers for the tasks and skills needed for successful self-care at home. Two studies measured patient and caregiver influences on hospital readmissions (Li, Morrow-Howell, et al., 2004). In a group of heart failure patients, Li, Morrow-Howell and Proctor (200) found that only self-reported medication adherence and length of heart failure history were significant predictors of patient readmissions. Patient functional status, heart failure severity, caregiver limitations and use of informal or formal paid caregiver services were not significant predictors of hospital readmission (Li, Morrow-Howell, et al., 2004). In another study, patient readmissions were associated with caregiver depressive symptoms and less tangible and emotional support, but the final readmission prediction model was not significant (Schwarz, 2000).

The variables in the quantitative literature reflected themes similar to those identified in the qualitative literature such as preparedness, knowledge, and coping. One study focused on preferences for discharge planning noted low agreement between seniors and caregivers (Huber & McClelland, 2003). This is an important area of further study, particularly the extent to which differing views on discharge planning contribute to hospital readmissions. Further, little is known about how transition conditions related to patient and caregiver relationships influence the effectiveness of hospital discharge interventions on transition responses.

CAREGIVER INTERVENTIONS TO FACILITATE HOSPITAL-TO-HOME DISCHARGES

Intervention-level research studies of hospital-to-home discharge transitions involving caregivers of seniors were examined to answer the fourth research question: what is the nature of intervention-level research of caregiver interventions to facilitate the hospital-to-home discharge transitions of seniors? Using the search methods previously described 11 studies were identified: five randomized control trials (RCTs) and six pilot and quasi-experimental studies conducted in the US between 2000 and 2013. Data were extracted using a code sheet to record relevant information such as the study design and conceptual framework, the discharge intervention and transition outcomes. Research quality was evaluated using a 20 point scale adapted from Brown (1991). Research quality scores ranged from 10 to 20, with a mean quality score for all interventional studies of 15.3 (SD=3.19). Three of the five RCTs specified the use of an intent-to-treat methodology which resulted in higher quality scores (Altfeld et al., 2012; Coleman et al., 2006; Naylor et al., 2004). Five of eleven studies described usual care for the comparison group (Altfeld et al., 2012; Coleman et al., 2006; Laramee et al., 2003; Li et. al, 2012; Naylor et al., 2004). The interventions were delivered at different points along the hospital discharge transition: pre-discharge, post-discharge, and combination interventions that included a pre- and post-discharge component. The results are summarized in Table 4.

Table 4. US Studies of hospital discharge interventions for caregivers published between 2000-2013.

Authors, Year	Purpose	Study Design	Sample	Intervention	Major Findings (Intervention vs. Usual Care)
Altfeld, Shier, Rooney, Johnson, Golden, Karavolos,. . . Perry, A. J. (2012).	Evaluate the effects of an enhanced DC planning program	RCT	n= 720, mean age 74.5 yrs IG: 360, UC: 360 CGs participated if patient unable, preferred, or CG present. Level of CG involvement not specified.	Pt and caregivers received intervention: • Identify and address problems • Assess pt / evaluate situation • Provide emotional support to pt and CG • Coach / educate on resources • Facilitate communication (pt/CG/team) • Support decision-making	Physician communication improved in IG: MD appt made (OR = 2.70) MD appt kept (OR = 2.09) No statistically significant differences in 30-day mortality or RA
Coleman, Parry, Chalmers, & Min, (2006).	Test the effectiveness of a care transition coaching intervention on rehospitalization.	RCT	750 community dwelling pts age 65+, hospitalized w/ 1 of 11 selected conditions. Final sample = 712 IG = 360 UC=352	Care Transitions Intervention: • Medication self-mgmt education • Hospital visit • Home visit • Phone call	Interv pts had lower RA rates • 30 days (8.9 vs. 11.9, p=.04) • 90 days (16.7 vs. 22.5, p=.04) • 180 days (8.6 vs. 13.9, p=.046) • ↓cost ($2058 vs. $2546, p=.049)
Laramee, Levinsky, Sargent, Ross, & Callas,(2003).	Test the effect of HF case mgmt on 90 day RA rate	RCT	Pts with HF Mean age 70.7 (11.8) IG: n=141, age 70.6 (11.4) UC:n= 146, age 70.8 (12.2)	• Early discharge planning • Patient and family CHF education • 12 weeks of telephone follow-up • Promotion of optimal CHF medications.	No sig diff in RA or LOS At 4 and 12 wks intervention pts had • Higher adherence to daily wt, low salt diet, fluid restriction, medications, • Higher satisfaction with hospital DC instructions

APN= Advanced practice nurse, CG=caregiver, CTI=care transitions intervention, DC = Discharge, ER = Emergency room, HF= heart failure, IG= Intervention group, LOS=length of stay, MD, medical doctor, Mo. = Months, pt=patient, OR=Odds ratio, RA = Hospital readmission, UC = Usual care control / comparison group, VA=Veterans administration, wk = week

Table 4. US Studies of hospital discharge interventions for caregivers published between 2000-2013.

Authors, Year	Purpose	Study Design	Sample	Intervention	Major Findings (Intervention vs. Usual Care)
Li, Powers, Melnyk, McCann, Koulouglioti, Anson, . . . Tu, X. (2012).	Evaluate the main effects of the CARE intervention	RCT Theory: Role theory; Self-regulation theory	407 Family CG-pt dyads IG: 202 CGs, 100 spouse, 102 non-spouse Attention control group: 205, 99 spouse, 106 non-spouse	Two session empowerment-educational program 1-2 days after admission and 1-3 days prior to DC consisting of audio-taped and written materials on participating in care and smooth hospital-to-home transitions. Control group: Two sessions on hospital services and policies.	No differences in patient or caregiver outcomes. Role-outcome and coping process differences noted at time 2, 1-3 days prior to discharge indicate that the intervention may benefit some subgroups.
Naylor, Brooten, Campbell, Maislin, McCauley, & Schwartz, (2004).	Examine the effectiveness of the APN Cost Quality Model of Transitional Care protocol	RCT	239 hospitalized w / HF IG: n=118, age 76.4 (6.9) UC: n =121, age 75.6 (6.5)	APN model provided continuity of care from pre-discharge to home setting • 3 months of case mgmt • HF protocol for chronic illness mgmt • 8 home visits	At 52 weeks, intervention pts had • ↓ RA (104 vs. 162, p=.047) • ↑ time 1st RA (X2=5.0, p=.026) • ↓ mean cost ($7636 vs. $12,481, p=.002)
Arbaje, Maron, Yu, Wendel, Tanner, Boult, . . . Durso, (2010).	Assess effect of Geriatric team on care transition quality & satisfaction with hospital care	Pilot cohort study	IG: 717 pts (or caregivers), mean age 79.4 UC: 351 pts, mean age 79.1 Pts without a CG excluded.	Pt and caregivers received intervention: • Geriatric MD / NP team assessment • Co-management geriatric syndromes • Staff education • Encourage patient self-management • Communicate w/ primary MD • Follow up soon after discharge •	No statistically significant differences in quality care transitions or satisfaction with inpatient care. Interventions provided during the week, no intervention for weekend admissions.

APN= Advanced practice nurse, CG=caregiver, CTI=care transitions intervention, DC = Discharge, ER = Emergency room, HF= heart failure, IG= Intervention group, LOS=length of stay, MD, medical doctor, Mo. = Months, pt=patient, OR=Odds ratio, RA = Hospital readmission, UC = Usual care control / comparison group, VA=Veterans administration, wk = week

Table 4. US Studies of hospital discharge interventions for caregivers published between 2000-2013.

Authors, Year	Purpose	Study Design	Sample	Intervention	Major Findings (Intervention vs. Usual Care)
Bull, Hansen, & Gross, (2000c).	Test the effects of a Professional-Patient Partnership model of discharge planning.	Quasi-exp, Before-after non-equivalent groups Conceptual framework: structure, process, outcome	n=180 Pt/CG dyads 158 dyad completed pre-DC and 2 weeks post DC Pt mean age 79.7 (8.8), range 55-94 CG's mean age 58.5 (14.9), range 20-86, 73% female 50% spouses, 38.4% adult children.	Staff educational program for nurses and social workers on DC planning assessment, pt and CG participation, and use of the pt / CG DC Planning Questionnaire (DPQ). • Pt / CGs completed the DPQ 1-2 days after admission • Pt / CGs viewed a videotape on preparing to leave the hospital and structured questions on post-hospital care to ask the MD, nurse, or SW • Pts were given a form to list medications + brochure on accessing services	1 control hospital implemented a DC clinical pathway during the study. 50% of pts / 60% of caregivers had difficulty managing symptoms and recognizing complications at 2 wks and 2 months after DC. CG scored continuity of information and services sig. higher at 2 wks and 2 months. No statistically significant differences in pt ER visits or RA at 2 weeks and 2 months.
Coleman, Smith, Frank, Min, Parry, & Kramer, (2004).	Preparing patients for self care after hospital discharge	Quasi-exp	IG: n=158 pts, mean age 75±6.4 Administrative data control group 1,245 pts, mean age 78.4±7.5	Care Transitions Intervention: • Med self-mgmt • Pt-centered record • Home follow-up • Self-mgt education, red flags for worsening condition	RA rates ↓ in intervention group • 30 days (OR=0.52) • 90 days (OR=0.43) • 180 days (OR=0.57) • 90 day ER visit lower in the intervention group, 18.3% vs. 25.7% (p=.046)

APN= Advanced practice nurse, CG=caregiver, CTI=care transitions intervention, DC = Discharge, ER = Emergency room, HF= heart failure, IG= Intervention group, LOS=length of stay, MD, medical doctor, Mo. = Months, pt=patient, OR=Odds ratio, RA = Hospital readmission, UC = Usual care control / comparison group, VA=Veterans administration, wk = week

Table 4. US Studies of hospital discharge interventions for caregivers published between 2000-2013.

Authors, Year	Purpose	Study Design	Sample	Intervention	Major Findings (Intervention vs. Usual Care)
Dellasega, & Zerbe, (2000).	Compare outcomes of a post-DC intervention for frail elderly patients.	Mixed method, Random assignment to treatment group (APN)	140 frail elders, mean age 74.3; significant baseline variability in the 4 groups (functional status, number of medications)	Pre-discharge visit in the hospital (w/ CG if possible) Hospital medical record review Discharge planning APN home visit 24-48 hrs, and 2 weeks post-DC, with other visits and phone contacts if needed (not described)	Pts in the RN only and RN+APN group had more informal services (p=0.*041*) CG outcomes had no differences in Caregiver Burden Inventory; Sig. differences in missed work days: No care group = 2, RN+APN=0, APN only=0, RN only group = 182.5 days.
Hendrix, Hastings, Van Houtven, Steinhauser, Chapman, . . . Weinberger, (2011).	Feasibility study caregiver training prior to discharge.	Pilot Theory: Self-efficacy Knowles theory of problem-centered adult learning.	50 pt-CG dyads Pts – 96% male > 60 (VA) CG- 92% female Relationship Spouse- 72% Adult child 18%	Caregiver training program lasted 1-1.5 hours, delivered when DC was imminent, conducted at the bedside to encourage pt involvement. Four teaching areas: • Medication management (15 minutes) • Red flags indicating worsening condition and how to respond (10 minutes) • Access to VA resources specific to pt/CG needs, show MyHealthyVet (15 minutes) • Specific caregiving issues – strategies for 2-3 caregiver priorities specific to care of patient at home (30 minutes)	Measures of self-efficacy and preparedness collected at baseline, after training, 1 and 4 weeks post-DC. Self-efficacy and preparedness were highest at T2, right after training w/ high scores sustained through Time 4.

APN= Advanced practice nurse, CG=caregiver, CTI=care transitions intervention, DC = Discharge, ER = Emergency room, HF= heart failure, IG= Intervention group, LOS=length of stay, MD, medical doctor, Mo. = Months, pt=patient, OR=Odds ratio, RA = Hospital readmission, UC = Usual care control / comparison group, VA=Veterans administration, wk = week

Table 4. US Studies of hospital discharge interventions for caregivers published between 2000-2013.

Authors, Year	Purpose	Study Design	Sample	Intervention	Major Findings (Intervention vs. Usual Care)
Li, Melnyk, McCann, Chatcheydan, Koulouglioti, Nichols, . . . Ghassemi, A. (2003).	Test effectiveness of a family CG intervention, "Creating Avenues for Relative Emplowerment.	Pilot Theory: self-regulation theory; interactional role theory	69 CGs recruited with 49 in final sample. IG CGs n= 25, mean age 63.6 (13.6), 68% female UC CGs n=24, mean age 57.9 (14.06), 58% female	Two Phases: (a) mutual agreement consisting of a plan for family CG activities during hospitalization; and (b) audiotaped information regarding emotional responses and possible complications associated with an elderly patient's hospitalization including instructions for participating in DC planning	No sig diff in CG state or trait anxiety or patient LOS or RA. IG= ↓ depressive symptoms (*p*=.01) ↑mutuality perceived (*p*=.03) ↑ CG hours per day (*p*=.04) All IG participants reported intervention helped and increased involvement. Family beliefs about behaviors and risks for complication may mediate intervention effects.

APN= Advanced practice nurse, CG=caregiver, CTI=care transitions intervention, DC = Discharge, ER = Emergency room, HF= heart failure, IG= Intervention group, LOS=length of stay, MD, medical doctor, Mo. = Months, pt=patient, OR=Odds ratio, RA = Hospital readmission, UC = Usual care control / comparison group, VA=Veterans administration, wk = week

Pre-discharge interventions

Of the five RCTs identified in the review, one was an exclusively a pre-discharge intervention which involved an educational program designed specifically for family caregivers (Li et al., 2012). The intervention involved audiotaped information provided to family caregivers at two time points: on the first or second day after admission and one to three days prior to discharge. Based on self-regulation theory and interactional role theory, the intervention included an information session and a mutually acceptable plan for participating in the patient’s care during the hospitalization. The second audiotape contained information on emotional responses, possible complications, and discharge planning. The usual care group received audiotapes on hospital services and policies. There were no differences between the intervention and control group in patient or caregiver outcomes, but differences in role and coping measures indicated that the intervention may benefit new caregivers who have more information needs about what to expect during hospitalization (Li et al., 2012). The pilot study of this intervention resulted in no significant differences in caregiver anxiety or patient length of stay in the hospital or hospital readmission. The researchers noted that family beliefs may mediate the effects of the intervention and experienced caregivers may already know what to expect from hospitalization and therefore did not benefit from the educational intervention (Li et al., 2003).

The professional-patient partnership model of discharge planning for elders hospitalized with heart failure was an intervention delivered exclusively in the hospital (Bull et al., 2000c). This quasi-experimental study was based on a structure-process-outcome model and consisted of staff education on discharge planning assessment, patient and caregiver participation in discharge planning, and the use of a discharge planning questionnaire to be completed by patients and caregivers. A videotape was provided to patients and caregivers on discharge preparation and questions to ask about post-hospital care. Patients were also given a form to list their medications and a brochure on how to access community resources and services. Data collection for one comparison group was confounded by the implementation of a discharge clinical pathway at one control hospital during the study time frame. Caregivers in the intervention group scored the continuity of information and services higher than the comparison group at two weeks and two months but there was no statistically significant differences in unplanned care as measured by emergency department visits or hospital readmissions at either time point (Bull et al., 2000c).

A pilot study to evaluate the feasibility of a caregiver training program was tested in a Veteran's Administration hospital (Hendrix et al., 2011). The 60 to 90 minute training program was delivered when discharge was imminent and was conducted at the patient's bedside to encourage patient involvement. Based on the theories of self-efficacy and problem-centered adult learning, the training was focused on four topics: medication management, red flag indicators of worsening condition and how to respond, access to resources, and specific caregiving issues related to 2 or 3 caregiver priorities. Measures of self-efficacy and perceptions of preparedness were collected at four time points and were highest right after training and were sustained up to the fourth time point four weeks after discharge. The qualitative evaluation was positive with patients and caregivers reporting feeling reassured to have one-on-one training with a nurse and addressed specific caregiver concerns (Hendrix et al., 2011).

In an adaptation of fixed-unit geriatric management unit, the Geriatric Floating Interdisciplinary Transition Team (Geri-FITT) model of care was pilot tested for feasibility and the effect on quality as measured by a caregiver survey 14 days after hospital discharge (Arbaje et al., 2010). The hospital system-level interventions included: staff education on the specialized services available from the Geri-FITT team, comprehensive assessment by a geriatric nurse practitioner, exploration of patient preferences, development of a geriatric care plan in consultation with a geriatrician, discharge needs assessment, and effective patient and caregiver preparation for the next site of care. Within 24 to 48 hours after discharge a one-page summary of the hospitalization and care plan was faxed to the primary care physician and the patient or caregiver was called to evaluate medication issues or medical concerns. The quality of transitions was measured by a 3 item care transitions measure, the CTM-3 (Parry, Mahoney, Chalmers, & Coleman, 2008) and four questions about satisfaction with inpatient care. The CTM-3 asks patients and caregivers about whether their preferences were considered in discharge planning, their understanding of responsibilities in managing health, and the purpose of medications. There were no significant differences in satisfaction about inpatient care or quality of care transitions between the floating Geri-FITT team and the comparison group. The usual care provided to the comparison group was not described.

Overall, the four pilot studies and one RCT that evaluated pre-discharge interventions focused on preparing patients and caregivers for the next step in care through empowerment, collaborative, comprehensive geriatric care, and caregiver training. The effects of the interventions were mixed but in general interventions delivered in person tended to be more effective than educational interventions delivered by recorded and print materials possibly due to increased feelings of engagement during face-to-face discharge-related interactions.

Post-discharge interventions

Post-discharge interventions are planned during the hospitalization but are delivered after discharge. Only one study tested an intervention provided to hospitalized seniors after discharge (Altfeld et al., 2012). In this study, seniors were randomized to an enhanced discharge planning program (EDPP) involving identification of patients aged 65 or older at risk for post-discharge complication using a hospital system-generated report from seniors’ electronic health records. Risk factors of interest included living alone, lack of a support system, high risk for fall, or complex psychosocial needs. All patients received usual care in the hospital. Patients randomized to usual care did not receive the baseline survey after discharge and all participants received a phone follow-up between 30 and 60 days after discharge. The EDPP social worker contacted patients or caregivers by phone within two days of discharge to assess the patient's needs and adjustment since discharge and administered a survey. After the call, social workers followed up as needed to make sure patients were getting services in accordance with the discharge plan, had filled their prescriptions, made a follow-up appointment with the physician, and made transportation arrangements if needed. Other resources social workers assessed for included other needs such as home delivered meals and psychosocial needs. The duration of the intervention was open-ended and patients were invited to contact the EDPP social worker if further needs arose. The average duration and intensity of the intervention were not reported.

Caregivers were the survey respondents in 30% of the cases (Altfeld et al., 2012). Patients or caregivers were asked about patient stress, caregiver stress, and questions about communication with the primary care physician. Over 80% of patients or caregivers reported at least one post-discharge problem with the largest categories of problems being self-management problems (45.8%), caregiver burden (35%), and coping with change (34.4%). The intervention group was more likely to make and keep an appointment with the primary care physician but there were no significant difference in 30 day mortality, readmissions, patient or caregiver stress or general health ratings (Altfeld et al., 2012).

Interventions bridging the transition

Five studies tested combined interventions that started in the hospital with discharge planning and preparation and included a post-discharge follow-up intervention. Three of the five studies were RCTs and two were pilot studies. All interventions were delivered by a masters-prepared advanced practice nurse (APN). Dellasega and Zerbe (2000) used a mixed-method design to test an APN intervention for frail rural elders discharged from the hospital involved a pre-discharge hospital visit with the patient and caregiver (if available) and follow-up home visits within 48 hours of discharge and again within 2 weeks. Data were collected at five time points: baseline, at the time of discharge, at 2 weeks, 1 month, and 6 weeks after discharge (Dellasega & Zerbe, 2000). This study was difficult to interpret due to low methodological quality. The data collected at various time points was not reported and it was difficult to determine what constituted usual care and what the APN did during the follow up visits. Data were reported according to four groups with relatively small sample sizes: no care, APN only care, home health visiting RNs, and APN plus home health RN visits. The only significant difference differences were that the 11 caregivers in the RN only group missed an average of 182 work days. There were no missed work days in the APN groups. This may have been due to an outlier case but possible causes of the disparate findings were not addressed in the research report.

The objective of another RCT was to evaluate the effect of heart failure case management on the 90 day readmission rate (Laramee, Levinsky, Sargent, Ross, & Callas, 2003). Intervention subjects had better adherence to self-management activities such as medication adherence, fluid restrictions, and daily weights and had higher satisfaction with hospital discharge instructions. There were no significant differences in readmission rates. The authors noted several possible reasons including measurement issues for adherence and heart failure severity, challenges with access to non-network physicians, and the lack of coordinated systems.

A pilot study (Coleman, et al., 2004) and subsequent RCT (Coleman, Parry, Chalmers, & Min, 2006) both tested the care transitions intervention provided by a gerontological APN who served as a transition coach. The intervention focused on four pillars: 1) medication self-management, 2) a patient-centered medical record, 3) post-discharge follow-up for medical conditions, and 4) instructions on monitoring for signs and symptoms of worsening condition to and actions to take. This bundle of interventions focused on ensuring post-discharge needs were met and continuity between the hospital and home setting to manage healthcare needs effectively (Coleman et al., 2006; Coleman et al., 2004). The pilot study demonstrated significantly lower odds of readmission in the intervention group. In the RCT, seniors receiving the intervention had significantly lower readmission rates and healthcare costs.

Naylor and colleagues (2004) tested the effectiveness of the APN Cost Quality Model of Transitional Care protocol was tested in an RCT of seniors hospitalized with heart failure. This intervention involved pre-discharge assessment, planning, and education combined with three months of disease management using a protocol and eight home visits. The effects of the intervention persisted and at 52 weeks the intervention group had a significantly lower readmission rate, longer time to first readmission, and a lower average cost (Naylor et al., 2004).

The three interventions with positive effects were comprised of combined hospital pre-discharge and home interventions to provide continuity between the hospital and home setting (Coleman, et al., 2006; Coleman et al., 2004; Naylor et al., 2004). In all three, caregivers were featured prominently and were described as key to positive transition outcomes for seniors. More work needs to be done on caregiver engagement and involvement with discharge interventions (Coleman et al., 2006).

INTERVENTIONS FOR FAMILY CAREGIVERS OF HOSPITALIZED PATIENTS WITH DEMENTIA

Phase II of this review involved identification of intervention-level research of hospital discharge interventions for family caregivers of with dementia. Three research studies of two interventions have been published (Boltz et al., 2014; McCauley et al., 2014; Naylor et al., 2007). The earliest study by Naylor and colleagues (2007) described foundational work on the APN model of transitional care tested on patient-caregiver dyads in the population of patients with cognitive impairment. A more recent study conducted a comparative effectiveness research trial on three interventions: an augmented standard care protocol (notify care team of cognitive deficits), a resource nurse model (nurses with experience and training designated as resource nurses available to assist as needed), and the APN transitional care model (McCauley et al., 2014). This study demonstrated the effectiveness of the APN model in decreasing avoidable hospitalizations and identified many challenges in testing these models in real world settings including role conflicts among APNs and other team members. The third intervention focused on functional and cognitive recovery of seniors with and without cognitive impairment to prepare the family for discharge (Boltz et al., 2014). This study emphasized the family caregiver role in influence care delivery and activity level of older adults noting that independence is a priority for older adults but physical activity is limited during hospital stays, particularly for those patients with dementia. Intervention patients were significantly less likely to be rehospitalized within 30 days and significantly more likely to recover to baseline function within 2 months of discharge. Family caregivers who participated in the intervention were significantly less depressed and anxious and more prepared for caregiving (Boltz et al., 2014). These three high quality intervention studies highlight the effectiveness of family caregiver interventions in improving hospital discharges for seniors with dementia. Although not a focus of this review, international researchers are also testing interventions to involve family caregivers to a greater extent and improve hospital discharge outcomes for seniors with and without dementia.

Limitations

This literature review has several limitations. Potentially relevant unpublished research was not included but no relevant citations of unpublished work were identified during the ancestry searching phase of this review. Restricting studies to research conducted after 2000 excluded early landmark work on transitional care models. This review focuses on current research conducted under current healthcare system conditions. This review excluded non-US studies in an attempt to decrease heterogeneity of interventions. However, an exploration of international studies may provide insights into the effects of specific interventions under different healthcare system conditions.

Gaps in the literature

Previous researchers have called for innovations in hospital discharge processes, teaching resources, and more time to prepare family caregivers for their role (Naylor & Keating, 2008) but few studies focused on family caregiver involvement. None of the studies that measured readmissions reported whether the readmission was caused by unmet needs resulting from insufficient discharge preparation or from failed post-discharge support. None of the studies focused on the relationship between health literacy and preparation and knowledge or interventions. Only one study examined cultural and socioeconomic barriers to smooth hospital discharge transitions. An examination of interprofessional literature on health literacy and communication may be helpful in tailoring hospital discharge interventions to overcome communication challenges.

Studies must be sufficiently powered to measure the differential effects of interventions based on various transition conditions such disease severity (Laramee et al., 2003). More work is needed to accurately evaluate the relative effectiveness of intervention components given that seniors and family caregivers have specific discharge needs (Naylor et al., 2004), such hospitalized patients with dementia. A better understanding of the caregiver perspective may reveal how multidimensional discharge interventions work synergistically to enhance caregivers' ability to manage the post-hospital care of patients with dementia safely and successfully at home.

Summary

The hospital discharge transition is a process characterized by increased interactions among seniors with dementia, family caregivers, and healthcare providers that takes place over time and typically includes hospital discharge activities such as discharge needs assessment, discharge planning, discharge teaching, and information needed for effective self-care at home. The most effective interventions combine assessment, planning, preparation, and post-discharge support. These comprehensive interventions have been shown to be the most effective in facilitating hospital discharge transitions, but the optimum frequency, duration, and combination of interventions is not known. Hospital discharge transitions for seniors with dementia is less studied but it is likely that all patients and family caregivers benefit from increased communication and collaboration with healthcare providers on individualized discharge plans that centered on patient and family goals, needs, and preferences. Seniors' and family caregiver roles are inextricably linked as care needs prompt reciprocal changes in caregiver roles and relationships. Family caregivers of hospitalized patients with dementia have a unique perspective on hospital discharge processes that may inform healthcare system improvements for this vulnerable population.

Chapter 3: Methodology

INTRODUCTION

The purpose of this study was to explore the hospital discharge process for seniors with dementia from the family caregiver perspective. Critical incident technique (CIT) is a flexible set of procedures used to collect observations of human behavior "in such a way as to facilitate their potential usefulness in solving practical problems" (Flanagan, 1954, p. 327). Critical incident methods provide a rich source of data because participants describe memorable incidents that are most relevant to their experience (Gremler, 2004). This chapter provides background on the CIT research method and describes the procedures established in this study.

In a CIT study, the unit of analysis is an incident, defined as "any observable human activity that is sufficiently complete in itself to permit inferences and predictions about the person performing the act" (Flanagan, 1954, p. 327). An incident is considered critical when the observer believes the activity had a significant influence on the intended outcome of the activity. Guided by the concept of significant events as described in transitions theory (Meleis et al., 2000), this study focused on family caregiver interpretations of healthcare provider actions that occurred during the hospital discharge process to prepare a senior with dementia for hospital discharge. It also included the family caregiver's interpretations of how those actions facilitated or inhibited the family caregiver's ability to support the senior at home after discharge. Critical incidents are not the discharge experience itself, but significant events that occurred during the discharge process that influenced the outcome.

HISTORICAL PERSPECTIVE

The critical incident methodology is rooted in observational studies of human behavior and aviation psychology studies conducted by the military in World War II to identify and categorize specific behavioral causes of good and poor performance (Flanagan, 1954). Much of the early research came out of the American Institutes for Research in the Behavioral Sciences located in Palo Alto, California (Fivars, 1973). The earliest CIT nursing studies in the 1950's and 1960's focused on behavioral indicators of job performance and professional nurse effectiveness (Abdellah & Levine, 1957; Bailey, 1956). Later studies extended this research to identification of effective behaviors of public health nurses (Glaser & McVey, 1961) and hospital staff nurse behaviors contributing to improved patient condition (Gorham, 1962). Further work on job performance was used to develop criterion measures for nursing practice (Abdellah, 1961) and to develop procedures for evaluating nurses (Rosen & Abraham, 1963).

Critical incident technique has also been widely used in nursing education research including evaluating student performance (Flanagan, Gosnell, & Fivars, 1963; Sims, 1976) and identifying indicators of effective teaching behaviors during nursing instruction (Barham, 1965). Many of these effective behaviors were related to showing learners how to work with a patient through modeling behavior instead of telling them what to do. These early studies using CIT methods were faithful to the behavioral focus outlined in Flanagan’s original work (Flanagan, 1954). A bibliography of early CIT work included 27 nursing studies of more than 600 total research studies (Fivars, 1973).

In the early 1980’s, researchers began using critical incident methods to explore perceptions and experiences. This work included studies of nurses’ professional growth and development including skill acquisition as nurses accumulate experience (Benner, 1982). Later work used critical incident recall and reflection as an education strategy (Minghella & Benson, 1995). These nursing education studies signaled a shift in CIT methodology from a behavioral to an experiential focus. Reed (1994) described adapting phenomenological and CIT methods to study nursing expertise in eldercare nursing. In this study, three interviews were conducted with nurses who were not able to identify significant incidents that demonstrated their expertise but were able to describe their approach to practice in generalities. Interestingly, students were able to provide specific incidents. The author proposed that as expertise increased, nurses were less able to recall specific details and experienced nursing practice in terms of overall patterns imbued with meaning (Reed, 1994). Several studies examined educator and student perspectives and incorporated elements of self-awareness and reflection on experiences using CIT to elicit perceptions and emotions from participants (D. L. Parker, Webb, & D'Souza, 1995; Rosenal, 1995). The phenomenological aspects of CIT were based the inseparable nature of interactions and interpretations and the special meaning that critical of events hold for the learner (Rosenal, 1995). For example, one study using CIT to explore nursing students’ experiences of empowerment and disempowerment focused not only the actions of others but how the students interpreted the actions (Bradbury-Jones, Sambrook, & Irvine, 2007). By encouraging learners to recall and reflect on specific types of incidents, educators can more effectively teach concepts such as patient dignity (Heijkenskjöld, Ekstedt, & Lindwall, 2010), and professionalism (Rademacher, Simpson, & Marcdante, 2010).

Critical incident technique has been used to elicit patient perceptions of health care since the late 1950's. Unpublished works were identified in the bibliography by Fivars (1973) including psychiatric patient perceptions of psychiatric nursing personnel (Fatka, 1958) and cancer patient perceptions of disturbances in the hospital (Greenberg, 1961). One study examined helping behaviors and positive interactions among patients in a psychiatric ward (Carter, 1959). Flanagan (1982) used CIT to examine patient expressions of quality of life. Consumer perceptions of health care quality have been studied in a variety of patient populations including residents of long-term care facilities (Grant & Hrycak, 1987), recipients of community oncology nursing services (Cox, Bergen, & Norman, 1993), and patients admitted to psychiatric wards (Beech & Norman, 1995; Kent et al., 1996). The perceptions of hospitalized patients have been studied to explore the quality of discharge procedures (Pryce-Jones, 1992), the quality of interactions with hospital staff (Rubin, 1993), and nursing care quality (Redfern & Norman, 1999a, 1999b). These studies used an interview approach except for one study that used postal surveys (Pryce-Jones, 1992). Redfern and Norman (1999a, 1999b) found that participants often gave overall impressions or composites of nursing care rather than specific incidents but were able to articulate what quality of care meant to them. There have been fewer CIT studies involving family caregivers. Research of family caregivers include CIT studies include examination of relational communication in support networks (Query & Wright, 2003) and exploration of control and loss of control in palliative home care (Munck, Fridlund, & Mårtensson, 2008).

All the critical incident studies of patients and caregivers perceptions of healthcare quality involved behavioral description. For example, in the quality of life study (Flanagan, 1982) the researchers asked about particularly satisfying activities and asked participants to describe a time when they were unable to do something they wanted to do (Flanagan, 1982).

Research has confirmed that CIT is a useful methodology for eliciting patient and caregiver perceptions of healthcare quality. Critics of CIT note that the flexible procedures can lead to inconsistencies in research methods (Sharoff, 2008). Many of the inconsistencies have arisen as the CIT method evolved from a focus on specific incidents to general impressions and shifted from a behavioral and interaction focus to experience, interpretations, and meaning-making. These methodological changes may influence the trustworthiness of research results (Bradbury-Jones & Tranter, 2008) and strategies to address these issues have been proposed (Butterfield, Borgen, Maglio, & Amundson, 2009).

CRITICAL INCIDENT TECHNIQUE RESEARCH METHOD

CIT has five basic steps: establish the aim, set specifications, data collection, data analysis, and interpretation and reporting the findings. This study used the enhanced CIT method which includes additional contextual questions to better understand the factors influencing family caregiver perceptions of hospital discharge transition processes (Butterfield et al., 2009).

Establish the aim

In this step the researcher developed a functional description or general aim of the activity under study to determine the objective of the activity and what a person who engages in the activity is expected to accomplish. The general aim of the activity was a simple phrase to frame the activity for the participant (Flanagan, 1954, p. 336). In this study, the general aim was the caregiver perspective of hospital discharge activities for seniors with dementia. Participants were asked to recount the hospital discharge transition process from the time they first became aware the senior was going home until the patient was “settled” at home.

Set specifications

In this step the research plan was developed and the significant events to be collected were identified. In this study, the significant events of interest were activities and interactions that occurred during the discharge process, particularly healthcare provider activities aimed at preparing the patient and caregiver for post-discharge care in the home. Inclusion and exclusion criteria were established. To be included the caregiver was directly involved in the care of a person over age 65 with dementia who had been discharged home from an acute care hospital for a medical or surgical condition in the past two years. Additional inclusion criteria were English-speaking and ability to participate in an in-person interview. Caregivers were excluded if they were unable to recall details of the hospital discharge process or if the care recipient was deceased. Some family caregivers resided with the senior and the importance of a private interview was discussed during the initial contact.

Recruitment took place through community sources including caregiver support groups, community centers, and senior centers. Informational flyers were sent to community contacts and shared at caregiver educational events. Purposive sampling was attempted in order to recruit a heterogeneous mix of family caregivers and a diverse sample of critical incidents. Letters of support were obtained from community organizations providing services to family caregivers including AGE of Central Texas and the Alzheimer’s Association. Recruitment documents are located in Appendix B: Research Study Documents.

Caregivers of persons with dementia are extremely busy and were difficult to schedule for interviews, often taking several weeks to months to identify a day and time convenient for the caregiver. In one case, 11 months elapsed between the time the caregiver first expressed interest in participating in the study and the actual interview. In the interim her father died, her mother moved to an assisted living facility, and her mother-in-law was hospitalized twice. Of 23 caregivers who expressed interest in participating in the study, only 8 ultimately scheduled and participated in an interview. Of these, one caregiver interview was excluded from analysis when it became clear during the interview that the patient did not stay overnight in a hospital and did not have dementia. Several caregivers had significant time constraints. For example, one caregiver was renovating her parents' home to prepare to sell it after they moved to assisted living. Several caregivers were the primary caregiver for more than one senior. Other caregivers were busy with job responsibilities and several were parents of school-aged children.

The caregivers in this study were unique in several important ways. They were all white females, affluent, and were savvy, well-educated caregivers who availed themselves of community resources such as caregiver support groups and respite programs. Four interviews took place in the caregiver's home while the care recipient was attending a respite or regularly scheduled adult day health services. None of the caregivers worked full time. Two worked part-time and two others volunteered as support group leaders. Only one was the primary caregiver for more than one senior and none of the caregivers had children living at home. All of the caregivers had at least one other person who was available to assist with some caregiving duties, including adult children and grandchildren, spouses, friends, close neighbors, and in one case the caregiver's mother lived in the home to help. Two caregivers had a healthcare background, one as a dental hygienist and one as a nurse. Another caregiver was highly skilled in managing difficult behaviors from her experience as a special education teacher.

Data collection

The sample size in a CIT study is based on “the number of critical incidents elicited rather than a specific number of participants” (Flanagan, 1954, p. 338). In this study, in-depth interviews of 7 family caregivers yielded 129 incidents for an average of 16 incidents per caregiver. This is consistent with other CIT studies such as study of perceptions of palliative care by Munck and colleages (2008) that identified 138 incidents from nine participants, an average of 15 incidents per participant. The number of incidents described by family caregivers exceeds the minimum of 50 incidents recommended to ensure there are enough usable incidents for data analysis (Schluter et al., 2008). Characteristics of the participants are outlined in Table 5.

A semi-structured interview guide was used to guide the interview (Appendix B.) The researcher explained the phenomena of interest to frame the study for the participant. Because the words “critical” and “incident” have particular connotations in healthcare these terms were not used during the interviews. Instead caregivers were asked about the “significant actions” healthcare providers took to prepare the patient for discharge (Keatinge, 2002). Because transitions are processes, the interview guide incorporated questions that capture the unfolding of the transition over time (K. L. Schumacher et al., 1999) such as when they first became involved in the discharge processes, and at what point they felt “settled” into a routine. Participants were asked about the events leading up to the hospitalization and whether the hospitalization was planned or related to a sudden change in the patient’s health. They were also asked when they became aware

Table 5. Characteristics of participants

	Caregiver Relationship	Hospitalizations of Senior with Dementia	Discharged To	Age	Gender	Race / Ethnicity	Healthcare Background
1	Spouse	NA – Excluded	Home	72	M	W	N
2	Spouse	Distant past – Open Heart Surgery Recent – Syncope Recent –overmedication, dehydration, syncope in shower	Home x 2	69	F	W	Y
3	Spouse	Recent – Car accident Recent – overmedication by assisted living staff Recent – seizures from medication withdrawal by assisted living facility staff	Assisted living x 2 Home x 1	62	F	W	N, Special education teacher experienced with behavior management.
4	Daughter	Recent – abdominal pain and passed out, cause hiatal hernia Multiple emergency room visits.	Home	54	F	W	Y
5	Spouse	Distant past – Traumatic brain injury ; Surgery , DC home w/ catheter d/t urinary retention Distant past – Post-DC CAUTI, severe requiring suprapubic catheter Recent – Sudden onset paralysis Recent – Fall, unable to move	Home x 3 Rehab facility x 1	61	F	W	N

Table 5. Characteristics of participants

	Caregiver Relationship	Hospitalizations of Senior with Dementia	Discharged To	Age	Gender	Race / Ethnicity	Healthcare Background
6	Spouse	Recent – pneumonia Recent – syncope Recent – syncope, dehydration Recent – syncope, arrhythmia, pacemaker	Home x 2 Assisted living x 1	76	F	W	N
7	Daughter	Recent – bowel surgery with readmission for acute renal failure Recent – dehydration & UTI	Assisted living x 2 Skilled rehab x 1	57	F	W	N
8	Daughter	Recent – planned urological surgery & home with catheter. Had ER visit and overnight observation stay post-dc for possible UTI & bleeding Recent – car accident Distant – gallbladder surgery	Home x 3	56	F	W	N

that discharge preparation activities had begun, and about the events and interactions that occurred in the hospital prior to discharge. Caregivers were asked about their interpretations of how the hospital discharge process, discharge preparation activities, and interactions with healthcare providers influenced their ability to manage after the patient was back in the home setting. They were also asked to describe how specific behaviors and interventions influenced the hospital discharge transition and to identify factors that were not present during discharge preparations but may have been helpful (Butterfield et al., 2009). Further details were allowed to emerge naturally as the family caregiver recalled significant events during the hospital discharge process and shared information that seem relevant to the caregiver. For example, instead of asking specifically about living arrangements, this data was collected only if it is expressed by the family caregiver during the interview. It is generally accepted that especially effective or ineffective actions are more easily recalled by observers (Schluter et al., 2008). Probing questions were used to elicit rich descriptions and ensure key elements of hospital discharge transitions were addressed. For example, if diet or nutrition did not come up during the interview then the researcher asked the caregiver if that had been a factor in the patient's hospital discharge.

Interviews were conducted at locations convenient to the caregiver such as the caregiver's home or local library. Interviews were audio recorded with a digital recording device. A contact summary sheet was completed immediately after each interview to summarize the overall interview and key points, and record field notes (Miles & Huberman, 1994). Interviews were transcribed verbatim.

Data analysis

Data were analyzed using inductive methods. Transcripts were read repeatedly identify of themes, subthemes, and contextual elements (Schluter et al., 2008). Content analysis was used to develop a categorization scheme that summarized the data while retaining specificity (Butterfield, Borgen, Amundson, & Maglio, 2005). Discharge preparation activities were categorized and subcategorized using an inductive approach. The use of subcategories preserved some of the detail of the underlying incidents (Flanagan, 1954). Constant comparative analysis was used to group incidents and categories across transcripts to determine when new categories no longer emerged from the data and saturation was reached. To minimize the influence of researcher bias during the analytic phase, each participant comment was questioned to prevent overlooking a key finding because of assumptions about the data (Schluter et al., 2008).

Interpreting and reporting the findings

Qualitative research findings are based on interpretations of the researcher (Denzin & Lincoln, 1994). In this study, the researcher examined each step for assumptions, biases, and decisions that could influence the interpretation of the findings (Flanagan, 1954, p. 345). The researcher's biases included the assumption that family caregivers were able to identify the personal factors that facilitated or inhibited the hospital discharge process and that the caregivers were able to describe salient interactions related to the hospital discharge process.

Trustworthiness

To ensure that a qualitative inquiry is viewed as a worthwhile advancement of nursing knowledge, four elements of trustworthiness must be addressed: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). Several strategies were used to enhance trustworthiness. The researcher's observations and decisions during the analysis and interpretation of data were documented through the use of a reflexive journal to document coding notes. Critical incidents, categories and descriptions were used as a basis of discussion with the research supervisor (Lincoln & Guba, 1985). As discharge interventions were categorized, the participation rate was examined to determine how many of the caregivers contributed incidents to each category (Butterfield et. al, 2009). When saturation was reached, the final categories were compared to the research literature to determine to what extent the categories are supported in the literature (Butterfield et al., 2009).

Protection of Participants

The research proposal was submitted to the School of Nursing Departmental Review Committee and Institutional Review Board (IRB) in accordance with University of Texas at Austin policies and was deemed IRB exempt.

Procedures for informed consent

Potential participants were given a basic description of the purpose of the study and participation requirements during an initial phone discussion. Informed consent was obtained prior to the interview. Caregivers were informed that consent was voluntary and they had the right to withdraw at any time. Risks and benefits of participation were explained including the possibility that they may experience emotional distress when recalling difficult situations or unpleasant interactions that occurred during the hospital discharge transition process.

Privacy and confidentiality

Participant confidentiality was addressed by assigning a unique case identifier at the time of consent. This number was used throughout the study to match demographic information with interview data. Names were not used and pseudonyms were assigned to people or organizations during the transcription process. Strict confidentiality was maintained throughout the duration of the study. Original consent forms were kept in a confidential notebook in a locked cabinet. Digital audio files and electronic transcripts were kept in a password protected folder on an encrypted laptop configured to allow access only by the researcher. After the data analysis phase was completed, the electronic files were removed from the laptop and were stored on an encrypted, password-protected external hard drive and will be retained by the researcher for 5 years.

SUMMARY

This chapter described the methodology of a CIT study and its usefulness in exploring caregiver perceptions of the hospital discharge process for patients with dementia. The steps in a CIT research study were reviewed including establishing the aim, setting specifications, collecting and analyzing data, interpreting and reporting the findings, and protection of human subjects. This study provided an opportunity to understand how hospital discharge-related interactions (or lack thereof) with healthcare providers were perceived by family caregivers. A better understanding of patient and caregiver needs may inform improvements that ease the hospital discharge transition for hospitalized patients with dementia and their family caregivers.

Chapter 4: Presentation, Analysis, and Interpretation of Data

INTRODUCTION

The purpose of this study was to explore family caregiver perspectives on hospital discharge processes and how discharge preparation activities and other factors influenced their ability to support the senior with dementia after hospital discharge. Meleis' middle range theory of transition provided the conceptual framework for this study. In keeping with critical incident technique, interview data were analyzed and interpreted to construct the following categories: providing person-centered dementia care, getting on the same page, maximizing function, managing medications, and post-discharge support. These categories are interrelated because of the complexity of hospital discharge processes and the associated interactions among healthcare providers, the patient, and the family caregiver.

PROVIDING PERSON-CENTERED DEMENTIA CARE

This category involved the extent to which healthcare providers recognized that the patient had a dementia diagnosis and what that meant in terms of influencing their approach to patient care overall and the hospital discharge process specifically. Person-centered care is an approach to care in which healthcare providers demonstrate respect for the unique characteristics of patients by individualizing care according to needs and preferences. The two subcategories, *recognizing dementia* and *taking a different approach* are inextricably linked as awareness of the dementia diagnosis is necessary for healthcare providers to realize that a different approach to care is needed and adjustments to the discharge plan may be required.

Recognizing dementia

Three caregivers described the importance of healthcare provider recognition that the patient has dementia. All three described the importance of being present at the hospital because the patient "covers so well" and the dementia may not be readily apparent to healthcare providers. This was described as a safety issue by one caregiver.

> I had to stay with her because she is a terrible historian and you don't get that right away when you talk to her. So you might go ahead and give her a medication she requests not realizing she has no idea what she is asking for.

Another caregiver attributed the fact that her father "covers so well" to a premature discharge. A friend was present when a hospitalist, who did not know the patient, made rounds and discharged the patient.

> When the doctor asked how he was doing, Dad said he was ready to go. So they let him sign his own paperwork and his friend brought him home. I couldn't believe it…I was so mad. They left his instructions and prescriptions in the room and I had to go back up there and get them.

Further, in this situation the nursing staff knew the patient had dementia yet still allowed him to sign his discharge paperwork without considering whether he had the capacity to understand what he was signing, nor did they confirm whether the friend who offered to drive the patient home was the appropriate person to receive the discharge instructions.

Another caregiver described rude behavior that was upsetting for the patient and the caregiver. This behavior was attributed to a lack of awareness that that the patient had dementia and resulted in the caregiver confronting a physician.

> the doctor got short with him and I got so mad and I followed her right out of the room and I said, “please don’t be short with him he has dementia, he can’t remember why he is here.” She apologized but it was right there, right on his drug list, and on his chart. You know? That is so frustrating. They should read the freakin’ chart.

This caregiver had a healthcare background and noted that before electronic health records, patient charts often had prominent notes taped to the front of the chart but with the advent of electronic health records, important information is not always readily accessed by healthcare providers. Awareness of a dementia diagnosis enables the healthcare provider to identify a patient’s needs and take different approach to the patient’s care as appropriate.

Taking a different approach

Even if healthcare providers are aware of a patient’s dementia diagnosis it may not influence their approach to patient care. One caregiver noted that the healthcare providers were aware of her mother’s dementia but that knowledge did not influence their approach to communication.

> They knew she did but it didn't seem to enter into the picture all that much… the doctors and the staff would come in and talk to her about stuff that there is no way she would understand and all it would do is frustrate her and scare her.

Caregivers described how healthcare provider attitudes about dementia influenced their approach care such as a lack of interest in providing therapy services. One caregiver noted: "they just see some old person with dementia. Her life doesn't mean much." Another caregiver described a difficult encounter with a physical therapy assistant.

> One of them got a little perturbed... working with people with dementia you can't expect them to remember everything but they still need therapy…the physical therapist said that she would like for him to work on upper body strength so this therapist assistant guy says, "no that won't do any good."

Most caregivers experienced multiple hospitalizations during their caregiving career. One caregiver contrasted two experiences at different hospitals. In the first hospital, nurses were knowledgeable in how to care for patients with dementia and had special equipment (a veil bed) so the patient could move freely unrestrained and still be safe. Just a few weeks later at another hospital she asked the nurses to obtain a veil bed for her husband and had a very different experience:

> Actually they had not even heard of it and didn't know what I was talking about. And I asked them about taking off the restraints…they said no because he would get agitated… they are supposed to come in every few hours when a person is in restraints and they didn't at all, and I know because I was there all day long.

Although both hospitals were in the same healthcare system, staff knowledge and equipment availability was inconsistent between the two hospitals. In addition to the discomfort of restraint, the patient was increased risk for adverse outcomes including deep vein thrombosis (DVT) due to restraint-related immobility.

Caregivers play a vital role in teaching healthcare providers how to work effectively with patients with dementia. One caregiver helped a therapist during a swallowing evaluation.

> I was explaining…he will probably have no problem but you can't just put crackers in front of him on the bed stand and expect him to motivate himself to pick it up and eat it because he doesn't see it - it doesn't process. I said if you put it in his hand…so she said "OK here's your cracker"…and I was like he is not going to be able to do that. But sure enough when she put the cracker into his hand he put it right in his mouth because it's automatic.

Caregivers also learn from knowledgeable staff members through observation.

> I would have never thought of that… she used a little dish and put the pills in there then pushed a part of a banana on it and gave it to him. And he would take it and eat it. And the pills wouldn't fall because they were stuck…she was giving them to him whole so they aren't crushed…when they put the crushed pills in the applesauce and mix it but then not give him all the applesauce… who knows what he got. And when you are talking about someone who is having behavior issues and antipsychotics…it seems like you would want them to get it all.

Providing person-centered dementia care influenced the hospital to home discharge process in several important ways. First, patients with dementia usually lack the cognitive ability to retain discharge instructions or to manage medications independently at home making it vital that family caregivers are involved in all aspects of discharge planning. Healthcare providers who recognize that the patient has dementia can customize hospital discharge planning activities to ensure that caregivers receive the information and post-discharge support needed for optimum patient outcomes.

Getting on the same page

Caregivers described a variety of communication-related challenges in terms of *getting on the same page.* This category involved caregiver efforts to get healthcare providers to see the patient as a capable person and ensure everyone involved knew the plan for discharge. Caregivers possess important knowledge about patients’ functional ability, home living situation, and management of patients’ care needs prior to hospitalization. It was important to caregivers that healthcare providers shared the caregivers’ understanding of patients’ functional abilities. This shared understanding was important to ensure that discharge plans were focused on maximizing the patient’s independence and health. Caregivers expressed frustration when they did not feel successful in getting healthcare providers to listen and incorporate patient capabilities into the discharge plan.

Seeing a capable person

Accurate and thorough assessment is the foundation of an effective discharge plan. Caregivers plays an important advocate role by helping healthcare providers see the patient’s capabilities and potential for recovery as part of the discharge planning process. Health care providers’ consideration of the patient’s baseline condition when developing the discharge plan was particularly important to two caregivers. One described a situation in which the healthcare providers wanted her to put the patient in a nursing facility when the caregiver and patient wanted the patient to return to assisted living.

> I felt like they didn't have a good assessment of her because she was on so much medication she was delusional so it looked like she was worse off than she really was. They treated her like she was an 80 year old woman who was completely incapable yet I knew before she was walking to get her hair done in the little beauty salon at her apartment. They didn't have a good assessment of what she was really like and I felt like their care and their treatment were exacerbating her problems. Things weren't as bad as they looked and it took a while to get everyone on the same page about what she really looked like and what she was really capable of. I had to get everyone on the same page.

This caregiver did not agree to a discharge plan that did not account for the potential recovery of the patient. Similarly, another caregiver described perceived substandard care after the patient had bowel surgery in terms of the healthcare providers' reluctance to recommend rehabilitation:

> This doctor one was telling me we just needed to call hospice. That she wasn't going to get any better. And of course she wouldn't, not with care like that! And she has been back in her apartment for six months now. So obviously it wasn't time for hospice.

Another caregiver recounted a situation in which she was unsuccessful in influencing the discharge plan because she could not get healthcare providers to listen.

> He was in such poor condition that they didn't see him for who he is…I remember pulling the nurse aside one day and telling her…he is in 4 positional restraints and gloves on and he can't communicate and he is flat on his back and it was NOT him…they saw him not as a capable person…the discharge was a mess and the care he got…was poor because they didn't know his capability and they would not listen.

The haste of the discharge process may be one factor that prevents healthcare providers from seeing a capable person. One caregiver who had recent experience with several elderly relatives stated "I always feel they are trying to rush them out before they are ready." Further, healthcare providers may not see a capable person because of insufficient assessment information. Two caregivers noted the brevity of physical therapy evaluations. One caregiver stated, "…it was very brief, not very thorough. She didn't really take him for a walk, just a few steps." Another caregiver described a situation in which the decision on the discharge destination was driven by a physical therapist. The caregiver wanted her mother to return to the inpatient rehabilitation program that had been interrupted because the hospital readmission. Instead of returning to the inpatient rehabilitation program to complete her therapy, her mother was sent back to assisted living facility against the caregiver's wishes.

> It was a so-called physical therapist who decided because she could walk with a walker from the bed to the bathroom door and back that she could go back to assisted living. And she only saw her one time, for a few minutes.

When healthcare providers did not see the dementia patient as a capable person, whether from attitudes, assumptions, or insufficient assessment, they were less effective in collaborating with the caregiver to develop an effective discharge plan that considered patient's and caregiver's needs and preferences.

Knowing the plan

Knowing the plan involves communication between the caregiver and healthcare providers on the expected discharge date and the arrangements for post-discharge treatments. Although medications are an integral part of discharge planning, a separate category for this topic was developed because of the scope and complexity of medication issues. It was clear that caregivers viewed the discharge plan as the hospital's plan but expected the plan to be individualized for the patient.

Caregivers were generally aware of the expected discharge date. In one case, the caregiver reported, “They said they were just going to keep him overnight and it was uneventful.” For two caregivers, incapacitated by injuries, the date of discharge was negotiated between the discharging physician and the caregiver. One caregiver stated:

> I was still in the wheelchair and his daughter she spent the night with him that night at the hospital, and she was exhausted. And so they agreed to let him come home instead of holding him for more tests.

Another caregiver was in a car accident with the patient. The caregiver was more seriously injured than the patient and was unable to care for the patient at home. She reported that the healthcare providers were empathetic and worked with her on the patient’s discharge date.

> It was kind of in my control in a lot of ways because they … knew that the assisted living couldn’t take him before a certain date. And so I think that is what drove the discharge date. I don’t think it had anything to do with his condition other than they wanted to make sure that he was going to a safe place…they would have sent him home with me but there was no way. Even if it had been just for a few days there was no way.

Caregivers were keenly aware that the discharge date involved the physician’s determination that the patient was ready to go home. Several caregivers described waiting for the doctor and one described communication as taking place during “those rare times when the doctor slides through.” Communication was particularly challenging if there was lack of agreement among the healthcare team about the patient’s discharge plan. One caregiver noted:

> It was more what they were talking about. What they were thinking the next steps would be. And when you catch them in the hallway, you never really know if they are even thinking of the right patient. And the prescriptions for therapy and treatment wouldn't be in agreement.

Another caregiver described a situation in which three hospitalists with varying opinions on her mother's condition gave inconsistent messages to other hospital staff:

> he was telling the case manager a different story than he was telling me about what the plan was… and the charge nurse, the case manager, and the doctors were all telling each other different things about how stable she was and different things about the discharge plan…which at that point really didn't have anything to do with her or what she needed.

This caregiver petitioned hospital administration to prevent her mother's premature discharge but was unsuccessful in influencing the discharge plan. She shared concerns "with anyone who would listen" that her mother's condition was not yet stable because of erratic blood sugar levels and having just been started on insulin.

> It was their plan, not a plan for her…the doctor was telling the case manager different things and everyone was telling and no one was listening…

As the caregiver expected, her mother was readmitted to the hospital for unstable blood sugars after just a few days in the rehabilitation facility. Her frustration was evident in recalling the situation:

Even when the discharge plan was agreeable to all parties, poor communication handoffs created dissatisfaction for some caregivers. One described an interaction with a rehabilitation facility admission nurse:

> She was very positive about …"we will get everything, we will line this up, we will get him on a regimen, and it's going to work well" but once we got there it

> didn't seem like she was talking to the people that were there so ...I was a little unhappy with their not seeming to be on the same page.

Lack of follow through and communication on a change in plan was disappointing for one caregiver:

> My big disappointment was the lack of follow through about the therapy set up, when they were going to arrange it and they didn't have that follow through… they suggested it so and I said yes and maybe it changed and they forgot to let me know…maybe the social worker thought the therapist would tell me and the therapist thought the social worker would let me know the plan changed.

Being present at the time of discharge was important to several caregivers. One caregiver was discharged the day prior to the patient's discharge.

> I trusted them that they had it well in hand and I checked with the hospital nurse and the assisted living…this is what they are planning and is that gonna work or do I need to come down because I can…get someone to take me…they probably felt like I didn't need to make the trip because they knew that was the only reason he was in that assisted living in the first place and they were trying to make it easier on me by saying that but it wasn't.

Another caregiver was surprised to discover her father had been discharged by the hospitalist the day after surgery, several days earlier than expected. The discharge occurred while she was away from the hospital on an errand.

> I told the nurse I had to run some errands and his friend from church was sitting with him. There was no telling when the doctor would come and I didn't want to miss what he had to say because his catheter had so much blood in it… so she put my phone number on the front of the chart with a note to please call me. By the time I got back home, Dad was already there.

This caregiver said that had she been present, she would have shared her concerns about the blood in the urine and had an opportunity to review the prescriptions and receive catheter management instructions from the discharging nurse.

Getting on the same page involved efforts by caregivers to influence the discharge plan by helping healthcare providers see the patient as a capable person and ensuring all parties knew the plan for discharge. Health care providers' attitudes and assumptions of the patient's functional status and recovery potential were sometimes based on insufficient information and limited assessments. Knowing the discharge plan was difficult when opinions varied or communications were inconsistent. Caregivers noted the importance of being present at the time of discharge and expressed disappointment and frustration when healthcare providers failed to follow through with discharge plans. Caregivers followed up with healthcare providers to arrange for services to ensure patients got the post-discharge care they needed.

Maximizing function

The category of maximizing function reflects caregivers' goals for patients to continue to do as much as possible for themselves for as long as possible. Caregivers recognized that hospitalization represented a setback and expressed a desire for therapy services after hospital discharge. Caregivers expressed the belief that physical therapy was vital in restoring previous self-care abilities and preventing functional decline that could eventually result in nursing facility placement. In many cases it was necessary for caregivers to advocate for therapy and follow up with healthcare providers.

Caregivers' focus on maximizing function was based on prior experience and learning from other caregivers. One caregiver described a proactive philosophy of caregiving in an attempt to make caregiving easier now and in the future:

> I really had a belief that would keep the person healthier and would make it easier on the caregiver. I saw some caregivers out there that…would tend to have family members that ended up...needing a lot more care earlier...and so my caregiving has been to push, push, push, you gotta do this, you are gonna go walk…it is very active in that way.

One caregiver noted that dementia-related cognitive impairment decreased the patient's motivation to stay active.

> I say he is a good sport, but he doesn't jump up eagerly. So he doesn't take initiative, it is a huge gap.

This caregiver also described the need to push her spouse to increase his mobility, stating:

> he can sink into the sick role really fast so I have to push him to get moving. He would love to sit around…. So when we got home I had to tell him…you have to do what you can do. I will be glad to help and give you guidance but you can't just sit around here.

For some caregivers, maximizing function of the patient was related to the caregivers' ability to continue providing care at home as they age.

> I want him to continue to be active because I want to be able to take care of him at home. I don't want to have to put him in a nursing home in two or three years because he is in really good health but he is no longer able to walk.

Another caregiver described her goal for her spouse who had been hospitalized with a sudden and unexplained loss of motor function in his legs:

> I want them to get him to where when he is on the floor, and he used to be able to do that, to put one knee up and get into a chair. But he hasn't been able to do that. We tried it but it took two people and 45 minutes to get him up. Yesterday he was …not able to function right so I am worried that he just isn't going to be able to and we can't continue like this as he gets older.

Caregivers worked to obtain needed therapy services for the patient. One caregiver commented that she had to insist that the patient be evaluated for home therapy services:

> The physical therapist came in at the very last minute, he was getting ready to leave the hospital, so she wasn't even sure she wanted to do it and I said yes I would like him to be evaluated and my understanding was they were going to recommend home PT. If that changed, they didn't tell me.

This example also reflects the haste of discharge and the challenge of getting on the same page during discharge planning. In this case the caregiver directly followed up with a home therapy agency they used in the past. Another caregiver noted that the importance of physical therapy was affirmed at post-discharge physician visits.

> …the last time he was discharged in October, the social worker came up and asked me if we discussed physical therapy and I said I wanted it and we never heard back and I thought she was going to recommend it but then nothing…we had a follow-up with his General Practitioner and we told her about it and so she said "Oh yeah he should have it," and so she ordered it….and then we went to see his cardiologist and he confirmed that yes it was really important and he said, "when her prescription runs out, I will write the next one."

Finally, one caregiver described the challenge of working with healthcare providers who did not share the caregiver's view of the value of therapy services. In describing an interaction with a physical therapy assistant, the caregiver noted:

> It seemed like he didn't feel like doing it and his rationale was we had everything we needed and he didn't need to be doing it with us…that is the first time I've ever felt like…why don't you pile it on the caregiver? You know the point is I tell him this stuff all day long…and I just needed someone else to help me tell him that is important. Just give me a break from it for just a little bit. Just help me

> drum it in, because he can tune me out really easily. That was my big disappointment, so I actually fired them.

These incidents reflect caregivers’ emphasis on maximizing the patient’s functional status so that the caregivers could maintain the patient at home for as long as possible. Caregivers persevered to obtain therapy services for the patient if they therapy was not included in the hospital discharge plan.

Managing medications

Managing medications was an area of focus from the time the patient was in the emergency room, on the nursing unit, and continued until medication issues after discharge were resolved. This category included ensuring that healthcare providers had a current medication list, patients received needed medications, and upon discharge caregivers had the information needed to manage medications effectively. Inattention to finely tuned pre-hospital medication regimens made patients worse, which influenced the healthcare providers’ decisions about discharge planning.

Caregivers reported multiple issues with medications. Caregivers expressed concerns about what would happen if vital medications were missed. The caregiver’s sense of urgency about her husband missing his medication escalated during a series of interactions after arriving in the emergency department (ED):

> I had the MyChart which lists his medications and I offered that at least twice…he has to have it because otherwise he is going to go beserk…

The caregiver was able to see her husband who was still in ED when she was wheeled up to a regular room. At that point his behavior was already escalating and he had not been medicated.

> He was freaking out because of the crash. So I figured if that is the way he was there then there is no telling how it was in the ER…that is why I kept pushing them and they were like, "Yes we will take care of that."

While she was in the radiology department, an emergency physician updated her on her husband's condition. The caregiver re-emphasized how it important it was for her husband to receive his medications.

> I said, "What time is it?" And he told me and I said, "You guys have GOT to give him his medication." "Oh yeah we will take care of that." And I thought, good OK. I said, "You understand the quantities?"

Several hours later, a nurse woke the caregiver to report the ER was having trouble managing the patient's behavior. The caregiver recounted the exchange:

> I got a nurse in my room who said, "They are calling us from the ER because your husband is kind of…he is not calming down." And I am like, "I told 3 people, one was his doctor and least another doctor medical professional and a nurse"…
>
> So it was 5:30 the next morning… I said, "GUYS it has been like 18 hours since he has had his medication OF COURSE he is going berserk on ya'…the only thing that is going to calm him now is Ativan and you are probably going to have to give 2 mg because the times we have been at the ER they have had to give the full amount right away to calm him because if you do the half then another half …it just doesn't work."

This caregiver did everything in her power to provide vital information to healthcare providers, but the information was not acted upon. She noted:

> That man was down in the ER for over 24 hours and at that point they had given him the Ativan…and then I got a nurse who came in and wanted me to go over his medications for the FOURTH time.

If the healthcare providers withheld the medications to avoid masking symptoms of a traumatic brain injury from the car accident, it was not communicated to the caregiver.

Although the focus of this research is hospital to home transitions, another caregiver reported a similar stressful experience when her husband did not receive needed seizure medications after transfer to a skilled nursing facility from inpatient rehabilitation.

> The discharge from rehab to skilled nursing was a huge nightmare with his medications seizure meds. You know we have been fine tuning these seizure meds a long time and have a regimen of meds at 6 o'clock, 12, 2, and 10 with certain meds at certain times so and when we left the rehab hospital and got to the skilled nursing they didn't have any meds. And so I said "can I bring his meds from home so he can have them?" and they said "no we have to have them dispensed." So I said, "There is a Walgreens right here. Can I have our doctors call a new prescription?"… "No, they have to come from Houston" and it was a day and a half before they got his seizure meds. And there was a tegretol one that they didn't carry that kind and it had to be special ordered. I said "Can I bring it from home?" and they said no. I was beside myself with worry that with having this thing on [gestures to mimic neck brace] and not being able to move and him having a seizure. And it was just… I was beside myself.

The caregiver took her concerns to two nurses and an administrator to no avail.

> Well I started at the nurse you know. Then I went and talked with the lady I talked to in admitting. And then to the director and it was just you know "these are the rules we have to live by" and you know these are the rules no matter the consequences. And he didn't have a seizure thank goodness. He had all other kinds of issues but not a seizure at least. Maybe he had enough drugs in him already. But oh I was worried.

The caregiver stated that she understood there may be regulatory requirements but expressed doubt that the intent of the rules was to prevent patients from receiving needed medications.

Communication between locations of care was problematic for some caregivers. Several reported having to go over medications multiple times. One caregiver noted a disconnect between the emergency room and the nursing unit:

> One of the problems I had... the nurses and the charge nurses…is that the medication list that they come into the emergency room with never made it upstairs. And they said that happens a lot that they don't communicate a lot with each other. Their computer systems are different or something and they don't get the information. It was unreal. I mean I couldn't believe I mean they told me that. They had to start completely over…and I had to go over it with them multiple times. Fortunately I had my own list.

Another caregiver attributed medication inaccuracy to haste in reviewing the patient’s medical records.

> They were in such a hurry when they looked at it they didn't pay attention…there were so many mistakes in the medications they were giving her… When the assisted living sends someone to the hospital they put together a packet of about 20 pages so they've got it…everything from the aspirin to Vaseline on her nails to keep her from getting a fungus. So they may not have bothered to go through all that.

Changing medication regimens sometimes worsened the patient’s condition. One caregiver reported that her mother was diagnosed with restless legs while in the hospital for a hiatal hernia. The hospitalist prescribed medication for the restless legs even though the caregiver told him it wasn’t really “bothering anyone.”

> They made it really hard in the hospital because she would have these restless legs and they would medicate it but it really didn't take it away. It just made her more

> out of it. So then she became like a crazy person yelling and trying to get out of the bed because she was loopy from the meds and no one was taking her seriously

Another caregiver described her frustration with the hospitalist. The patient was on over thirty different medications between the cardiologist, nephrologist, and primary care physician. None of these physicians were consulted when the hospitalist changed the patient's medication regimen.

> It's like when the hospitalist gets in there he has this God-complex thing like anything anyone was doing before goes out the window and he is going to start over and do what he wants to do and whatever happens after that is someone else's problem. And that is the attitude that they all seem to have. It's unbelievable when you are in the middle of it.

One caregiver successfully prevented a change in medication regimen after her husband was transferred to the hospital by assisted living staff. She insisted no medications be given until she could speak with the patient's psychiatrist.

> When I got there they were ready to give him Keppra. And I said, "What I understand from the description that it wasn't a seizure. That was a myoclonic jerk." And I said, "I don't want you giving him Keppra because he is not in any obvious distress right now. And I want to talk to a doctor before you do it."

Confusion about medications at the time of discharge was a concern for several caregivers. Caregivers had learned the importance of medication adherence over time from the patient's healthcare providers and feared making an error. One caregiver had questions and contacted the hospital for clarification:

> I called them and asked them about his medications. We got home and had the list but I couldn't tell what they gave already that day…my question was for the ones that were twice a day, did you give them already? And they were like "we don't know." I called the nurses desk and they didn't know and they said his chart was

> already gone from the station. I talked to his nurse and she said, “his records are already gone so just start it tomorrow.” She was like “yeah, he would have gotten it”…but she wasn’t sure and she wasn’t worried, but I sure was.

Complexity of the medication regimen can also be a concern for caregivers. One caregiver noted:

> One of them was a prednisone package where it is like six one day, then five the next day, like that and I thought oh boy. And the pharmacy didn’t have the exact pill size so they changed it around a little bit. Oh and he had antibiotics a certain number of hours apart. And I hoped I could keep it all straight, and I did, but it was a little scary.

Even when patients reside in assisted living facilities, caregivers have considerable medication responsibilities. In some assisted living facilities, it is the caregiver’s responsibility to clarify medication orders with the patient’s physician. The hospital records were confusing in one case:

> I had to go through it item by item when we got back because the hospital records were confusing. We had two different orders for insulin.

Another caregiver had to contact the hospital physician because the assisted living facility staff was confused by the discharge medication list which contained all the medications the patient had ordered in the hospital. Because the caregiver had been injured, she coordinated the medication reconciliation by phone and made phone calls to get the assisted living a medication list they would accept.

> They said, “We are all set, we will coordinate it with the facility.” I was like great, because again, I was not able to drive myself…it would have been really difficult…so he was moved and as soon as he got there I got a call from the facility…and they said “they have changed his medications all around. He was

> taking Allegra and they put him on Cingulair and he is supposed to be taking Glucophage" and I am like, "wait a minute, no, no no no no."
>
> So I went through it…Coumadin, I thought nope they did that because he was on his back, he was restrained they weren't letting him move and they wouldn't even let him up to go to the restroom and they were afraid of you know the vein stuff. And so I am like I kind of doubt they meant for him to be on all that…and doctor had not given him prescriptions. There were breathing treatments, and other stuff on the list…. that was not meant to be an ongoing treatment so I contacted the hospitalist…and his primary care doctor and explained the situation to both of them. The hospitalist finally called me back and she is like "what is it they want?" And she said the same thing, "Those were the drugs he was given in the hospital. They should be going right back to what he had before, none these are needed for his ongoing care."

One experienced caregiver anticipated medication issues and arranged for a physician visit the day after discharge. When asked about what specifically concerned her about the medications and why she contacted the physician office, she stated:

> Oh everything, all of it. Medications she wasn't on before that it turned out she wasn't supposed to be on because of her kidneys…every time any time any of our parents have been in the hospital we've come home with problems with medications. Every single time.

Caregivers were concerned with all aspects of managing medications from ensuring the health care providers had a current medication list, checking the medications the patient received in the hospital, and reconciling medications after the patient was discharged. Medication issues worried the caregivers, who tried to work with healthcare providers to prevent discharge-related adverse drug events.

Post-discharge support

The category of Post-discharge support includes getting needed information, arranging for services after discharge, and calling for help.

Getting needed information

Caregivers needed information to safely care for the patient at home. This was a challenge for some caregivers when healthcare providers assumed did not need additional information.

> So yeah a little bit more explanation. I think sometimes when you are capable as a caregiver sometimes the professionals assume you know more than you do.

Another noted the need for information about psychological aspects of care.

> With the bypass a lot more explanation and um a lot more this is what you should look for and this could happen. I stayed awake with him all night long on a number of nights because he was afraid he would stop breathing.

This caregiver was dismayed to learn a few months after the patient's discharge that psychological symptoms are common after being on a heart bypass pump, yet no one mentioned it before discharge. In this couple's case, the lack of sleep impeded the patient's recovery and led to caregiver exhaustion. Friends noticed that the patient had changed and the caregiver stated he was very depressed.

Caregivers were appreciative when they received written information. It was particularly helpful for caregivers who had documentation that met facility record requirements.

> She was given discharge instructions and it was written. The medication list was appropriate and it was just like the medication list that I had given to the nurse the day or two days before when they were asking about his medicines…it was the same, it didn't have you know change to this and change to that and telling you to go see your family doctor and all that sort of stuff. That to me was really smooth and a great deal of information. Like I said it was 8 or 9 pages and it was exactly what the assisted living needed to be able to use for their input without having to have a regular family doctor to sign off on his admission.

Caregivers also appreciated reiteration of information they already knew but had not implemented. A caregiver who is also a registered nurse noted:

> There were some explanations about the medicines and we talked about how to make sure she remembered to take it. They had some good ideas on how to set up checklists and things and they were just the basic things that I knew but we weren't really doing.

It was helpful to caregivers when the discharging nurse reviewed the discharge paperwork with them:

> They go through each page and explain what is in it. It is just a mind-filling experience, so not everything fits in. And we get home and think now what did they say, so it is good to have all this in writing. And so the main thing that would have helped if they had checked off which medications he already had that day, so I could pick up where they left off.

Healthcare provider assumptions about caregiver knowledge contributed to unmet information needs. Caregivers got needed information when healthcare providers provided written information and reviewed it with the caregiver.

Arranging for services after discharges

Caregivers often coordinate care for the patient after discharge, such as arranging for home therapy as previously described. Healthcare providers in the hospital may not be aware of the patient’s health history or other treating providers, limiting their ability to coordinate care. One caregiver wanted to make sure the outpatient healthcare providers received any relevant hospital records:

> Sometimes the doctor doesn't even know their patient has been in the hospital. Even specialists…her cardiologist’s name never was put on the chart and they didn't even know she had a cardiologist…she was having all this edema and I know the assisted living records they sent has all of her doctors listed. They just didn’t even look at it…even with the congestive heart failure and all that…I told them to make sure they sent all their hospital records to her cardiologist and they said "she has a cardiologist? Who is it?" And that could have been assisted living not telling them. But even if they told the ER, the ER would not have told them upstairs. If they don't even tell them the medications why would they tell them about the doctors? They just didn't bother to look in the records.

Another caregiver was concerned with venous stasis ulcers, noting that the physicians were interested in treating the edema and were not as concerned as she was about the wounds. This caregiver arranged for wound clinic services after she learned about this community resource from a coworker:

> So I was treating the sores myself and they told me to get a compression hose and a wound stocking that goes on first and of course I was doing all this and it was painful to him. And my boss was going over to the wound care clinic and she told me, “You have got to get him over there.” So I took him over but no one ever told me to.

Caregivers had different experiences with assisted living facilities. One caregiver described a smooth transition home from recuperating at an assisted living where she was recovering from a broken ankle and he was staying in an adjacent room.

> [Name of assisted living facility] took care of all that to make sure that [name of home care agency] started on day one. And they took our list and went to the store

> for us, and stocked up on the frozen foods we like. I got around a lot better than I thought I would, even in a wheelchair.

Another caregiver described minimal support from a different assisted living:

> Yeah it seemed like that particular facility everything was dumped in the family's lap…if you didn't do it then you were quicklined out the door. So it is kind of like if you didn't fit in their box they don't want to deal with it.

Caregivers commonly arrange for services after discharged based on their observation of unmet patient needs.

Calling for help

Caregivers described situations in which they followed the discharge instructions but did not receive the help they needed. One caregiver called the physician but he was not helpful.

> They sent him home with a catheter because he couldn't urinate and the catheter came apart at home…I called the doctor and asked him "how do I get this thing back together?" And he was… it was just ridiculous talking to him. Either he didn't know or he couldn't explain it…it completely ridiculous. So I drove him back to the emergency room and they changed it and we went home.

Another caregiver noted that she was given the opportunity to ask questions but wasn't sure what to ask and wasn't sure who to call anyway.

> Because it is all anticipatory while you are still there and until you get home you have no idea what it is going to be like…but if you needed something, who would you call? The nurses at the hospital wouldn't know and the hospitalists take turns so they aren't there every day and there is no continuity with them.

Two caregivers noted the helpfulness of online patient portals to ask primary care physicians questions. These caregivers expressed how helpful it would be to have an online inpatient portal to ask questions.

One caregiver noted that it was helpful when the primary care physician would call to check on the patient to ascertain if a treatment change was effective.

> She would call at the end of her day, sometimes at 8 at night just to check to see if something worked out. So we had good follow up care from our primary care doctor.

This personal attention conveyed a sense of caring that left the caregiver feeling well-supported. Several caregivers reported that the primary care physician was responsive when the caregiver reported that the patient had been in the hospital. None of the caregivers reported receiving follow-up phone calls from hospital-based healthcare providers.

Post-discharge support was provided by the patient's primary care physicians and specialists. Caregivers actively advocated for and arranged for post-discharge services, such as physical therapy, after discharge.

Summary

When dementia patients are hospitalized, the caregiver shoulders a tremendous burden that starts with ensuring healthcare providers are aware of the dementia diagnosis and the medication regimen. Caregivers felt responsible to stay with the patient at all times to prevent untoward outcomes and did what they could to influence the discharge planning process. Overall, caregivers described the hospital discharge process as “chaotic” and “a nightmare.” These incidents reveal that discharge plans were rarely person-centered and were often based on healthcare provider assumptions rather than thorough assessment of the patient’s condition, needs, and preferences. Caregivers were concerned about patients’ independence and were focused on maximizing function and arranged for post-discharge services as needed. Medications were a significant issue and healthcare providers’ lack of attention to finely-tuned medication regimens often made patients worse. After discharge, caregivers worked with community-based healthcare providers to get the patient’s medications recalibrated. Post-discharge support came mostly from community-based healthcare providers who had an established relationship with the patient and was trusted by the caregiver.

Not all the critical incidents described unmet needs. Caregivers also described positive experiences such as nurses who took time to sit down and review written discharge materials or answer questions. One caregiver still had her husband’s hospital discharge packet even though several months had passed. Another described a nurse reviewing the discharge medication list and took care to note each change from the medications the patient had been taking prior to admission. The complexity of the regimen was stressful to the caregiver, but she was able to successfully manage the patient’s medications. Written discharge instructions were helpful to caregivers.

None of the caregivers reported receiving post-discharge support from the hospital such as home health services or a post-discharge phone call. The caregivers participating in this study successfully coordinated the patient’s care on their own after discharge. They arranged post-discharge follow-up appointments with the primary care provider and specialists, provided valuable information on the change in the patient's condition and response to hospital treatments, and obtained orders for therapy services and a wound care clinic referral when needed.

Although, significant opportunity exists to improve the hospital discharge process for patients with dementia and their caregivers, these caregivers were able to cope with the challenges and learn from their experiences, allowing them to anticipate similar challenges during subsequent hospitalizations.

Chapter 5: Discussion and Implications

This chapter provides an overview of the study and situates study findings within current literature. As the consistent patient advocate before, during, and after each hospitalization, caregivers provided valuable information on interactions with healthcare providers during the hospitalization and discharge of patients with dementia. Implications for practice, education, research, and policy are identified.

OVERVIEW OF THE STUDY

The purpose of this study was to explore family caregiver perspectives on hospital discharge processes and how discharge preparation activities and other factors influenced their ability to support the senior with dementia after hospital discharge. Consistent with critical incident technique, family caregivers were asked to reflect on the hospital discharge process and describe interactions with healthcare providers aimed at preparing the patient and caregiver for discharge from the hospital to the home setting.

DISCUSSION OF RESULTS

This study used the lens of Meleis' middle range theory of transitions to explore the family caregiver perspective of hospital to home discharges of patients with dementia (Meleis, 2000). This framework emphasizes the interactions between patients, families, and healthcare providers during times of transition in which therapeutic interventions are tailored to the needs of the patient and caregiver based on transition conditions. A person-centered approach to therapeutic roles and relationships positively influences patients' and caregivers' patterns of response (Meleis, 2000.) Health care providers have a lot to learn from patients and their caregivers about how careful assessment of transition conditions, especially insight into relevant personal factors, can guide the development and implementation of effective discharge plans.

In terms of nursing therapeutics, the recommended components of ideal hospital discharge processes are well known and include thorough assessment of discharge needs and resources, developing a collaborative discharge plan, communicating among healthcare providers, and coordinating care and services after discharge (Bull & Roberts, 2001). Over the past 30 years, transitional care interventions have been developed that start in the hospital and continue for a period of time when the patient is in his or her home. These services bridge the gap between inpatient and outpatient settings. Examples of these effective models include the advance practice nursing transitional care model (Naylor et al., 2007) and the Care Transitions Intervention delivered by transitions coaches (E. A. Coleman et al., 2004). Although these interventions are promising, the costs of these programs are often grant-funded and not factored into current hospital reimbursement models.

Initiatives are underway to improve hospital discharges such as the re-engineered discharge, Project RED, which includes the following components: education about the diagnosis, appointments for follow-up and testing, organizing discharge services, confirming the medication plan, reconciliation of the discharge plan with standards or guidelines, review the steps to take if a problem occurs after discharge, expedited summary of the hospital stay to post-acute healthcare providers, evaluation of patient understanding using the teach-back method, a writing discharge plan and telephone contact within 3 days of discharge for questions and problem solving (Markley et al., 2013). A similar initiative, Project BOOST is focused on reducing rehospitalization (Hansen et al., 2013). The key components of this model are an intervention toolkit to prevent adverse events, an implementation guide, physician mentoring, and participation in a BOOST collaborative with other hospitals. Interventions in the toolkit include: a hospital risk assessment, a universal discharge checklist, discharge preparedness assessment, patient and caregiver education tools, teach back to confirm understanding, communication among healthcare providers including a discharge summary within 48 hours of discharge, and a follow up phone call within 72 hours (Hansen et al., 2013). These voluntary initiatives require a significant commitment of time and resources to fully implement and evaluate. Often quality improvement efforts result in uneven or incomplete implementation and may not be sustained over time if attention is diverted to other pressing priorities.

Despite successes at some hospitals, improvements in hospital discharge processes are inconsistent (even among hospitals within the same healthcare network) and caregivers continue to report unmet care needs. Caregivers in this study expressed several issues that were common across several studies. These issues included the chaotic, rushed nature of the discharge (Fuji, Abbott, & Norris, 2012), poor communication (Kimmel, Sullivan, & Rushakoff, 2010), lack of control (Porock, Clissett, Harwood, & Gladman, 2015), lack of caregiver involvement in decisions about care (Jamieson, Grealish, Brown, & Draper, 2014), and lack of coordination among healthcare providers (Kelly & Penney, 2011). Caregivers echoed the sentiments of caregivers in other studies who described feeling of being undervalued and excluded from decision-making even though the caregiver is the expert regarding the patient (Bloomer, Digby, Tan, Crawford, & Williams, 2014).

Recommendations for improving hospital discharges for patients with dementia and their caregivers include evaluating discharge needs soon after admission and involving family caregivers in discharge planning (Silverstein & Maslow, 2006). Starting the hospital discharge process earlier in the hospital stay allows time for healthcare providers to get to know the patient by engaging family caregivers in discussions about the home environment, caregiving situations, and anticipated changes in care needs. One successful model, led by a geropsychiatrist, included careful management by a trained transitions nurse who assessed the hospitalized patient for discharge needs and facilitated communication between inpatient and outpatient providers. This program built trusting relationships among healthcare providers and resulting in improved care for patients and caregivers (Tew, 2012). However promising, these types of enhanced services can be time-consuming for healthcare providers, are associated with significant costs barriers to implementation, and are difficult to sustain in the current economic climate (Dedhia et al., 2009).

Providing Person-centered Dementia Care

Nurses’ ability to provide person-centered therapeutic interventions depends on recognition that individual patients have different needs and preferences. Caregivers in this study described interactions as stressful when healthcare providers didn’t recognize the patient had dementia or understand what it meant. Screening tools, such as the three-word recall and clock drawing tests, have been used to identify cognitive impairment older adults, and has been identified as a useful marker of post-discharge risk for rehospitalization and mortality in the heart failure population (Patel et al., 2015). Similar strategies can be incorporated into admission assessments to identify dementia patients.

Standard hospital care processes did not accommodate the unique needs of the patient or caregiver. Consistent with other studies, caregivers in this study noted that healthcare providers were sometimes abrupt with or frustrated by patients and lacked the knowledge and skills to effectively work with a person with dementia (Spencer, Foster, Whittamore, Goldberg, & Harwood, 2013). Caregivers in other studies have commented that hospital staff were not adequately trained on behavioral management (Porock et al., 2015) but researchers have been challenged in their efforts to demonstrate the effectiveness of dementia training programs (Smythe et al., 2014). One study compared the care provided on a dementia specialty unit with standard hospital care. The specialty unit had an activities coordinator to engage patients and training to increase staff knowledge and skills in dementia and behavior management. However, even on a dementia specialty unit, family caregivers reported unmet needs and recommended improved communication and collaboration (Spencer et al., 2013). Dementia training and increased knowledge of dementia care is not sufficient to improve patient outcomes; healthcare providers must also change their approach to care and practice behaviors. Using an appreciative inquiry approach to discover the positive aspects of dedicated dementia units in a hospital, researchers emphasized the importance of relationships, specifically the “extended dementia care triad,” which includes patients, family caregivers, and healthcare providers (Scerri, Innes, & Scerri, 2015).

Family caregivers in this study described negative attitudes of healthcare providers towards the person with dementia and a lack of attention to these patients. Hospital care can be experienced by patients and caregivers as impersonal and dehumanizing, yet initiatives such as the Dementia-Friendly Hospitals program have had a positive impact on staff attitudes and approaches to care (Galvin et al., 2010). This educational program includes information to improve communication with patients and caregivers and adjustments staff can make to suit the needs of patients with dementia. Further, in an ethnographic study of hospital nursing care, researchers observed that nursing work was organized around documentation in an electronic health record, such as completing required assessment forms and checklists (Rankin, 2015). Because nurses’ were focused on usual or standard care pathways and technological tasks requirements, nurses had difficulty identifying and attending to patients’ unique needs and providing individualized care (Rankin, 2015).

The caregivers emphasized the importance of healthcare providers seeing the patient as a capable person whose life had meaning. In order to provide person-centered care, healthcare providers must have some knowledge of the patient and caregivers' needs and preferences (Clarke, Hanson, & Ross, 2003). Adopting person-centered care practices can improve healthcare provider attitudes toward hospitalized seniors (Pope, 2012) and may extend to family caregivers. In the current study, caregivers described being perceived as demanding because of their efforts to "stay on top" of the nurses, communicating unmet patient needs and "eagle-eyeing" care delivery to ensure patients received needed care. Similarly, caregivers in other studies described efforts to advocate for patients that were met with resistance by some nurses who characterized the vocal caregivers as "difficult to deal with" (Rankin, 2015). A "cycle of discontent" has been described an exploration of dementia caregiver discontent with hospital care in which caregivers perceived poor care or treatment and became hypervigilant, resulting in conflict or avoidance (Jurgens, Clissett, Gladman, & Harwood, 2012).

A person-centered approach to care is ideal for hospitalized patients with dementia but is challenging to achieve (Clissett, Porock, Harwood, & Gladman, 2013). Person-centered approaches to care take time to develop and are more conducive to long-term relationships and may be difficult to implement during episodic short-term acute inpatient hospital stays (Clissett et al., 2013). These challenges highlight the importance of taking time to involve caregivers and get to know the patient so that the care provided can be tailored to the patients' and caregivers' individual needs. One study tested a strategy to quickly learn about a patient needs and preferences involved using a structured communication process. Healthcare provider engaged caregivers in a conversation about the top five most important tips and strategies to care for the patient with dementia. This information was documented on a “Top-5 form” and placed on the patients chart to be used by clinical staff in individualizing care (Luxford et al., 2015).

Involving Caregivers

As emphasized by the study participants, person-centered dementia care requires that healthcare providers know something about the patient needs and preferences. This key information is held by family caregivers and more importantly family caregivers are the only consistent person throughout the discharge transition process. Caregivers possess valuable information about the patient but the study participants described being disregarded by healthcare providers even when the information would be helpful in caring for the patient. This sentiment was described by caregivers in one study who described a power imbalance where knowledge and information was not shared and caregivers expressed feeling left out because of a lack of involvement in treatment or discharge plans (Dilworth, Higgins, & Parker, 2012). Similarly, caregivers in another study described hospital discharge planning as a paradoxical experience in which they were expected to stay with the person and provide supportive care to the patient yet were excluded from discharge decisions and planning. (Jamieson et al., 2014). They also described an uncoordinated discharge with caregiver notification only when discharge was imminent (Jamieson, et al., 2014).

Caregiver engagement and support can increase the effectiveness of hospital discharge interventions, ease the transition process for patients and caregivers, and prevent hospital readmissions (Kripalani, Theobald, Anctil, & Vasilevskis, 2013). A key feature of the most effective discharge interventions is intentional family caregiver engagement. This focused attention to engagement resulted in practice shift in one hospital and created a culture of care where healthcare providers now routinely engage family caregivers (Naylor & Marcille, 2014). Another intervention involved family caregivers in direct patient care using a Family Involvement Menu (Wyskiel et al., 2015). The menu listed tasks family caregivers could do for patient with the goal of creating opportunities for early caregiver education and building therapeutic relationships that would ultimately better prepare patients and caregivers for discharge (Wyskiel et al., 2015).

Communicating Effectively

This study's caregivers described several challenges in communicating effectively with busy nurses and physicians. Obtaining desired information was described as an unpredictable process of trying to catch physicians in hallways and "bothering" or interrupting nurses during scheduled tasks such as medication administration. This is consistent other findings in which caregivers were dissatisfied with communication, medical management and discharge planning (Lipson et al., 2006; Whittamore et al., 2014). Further, there is still no regular process for involving patients and caregivers in team conferences where discharge decisions are made resulting in discharge plans which may not be communicated back to the patient and caregiver (Congdon, 1994). Caregivers also described barriers when trying to access and obtain patient care information and recommended that the convenience of electronic portals in community physician practices be extended to the hospital setting. Sarkar and Bates (2014) identified data privacy and security as a barrier to information sharing, even for patients and caregivers who need to be identified in the medical record for continuity of care and better documentation of caregiving.

According to LaMantia and colleagues (2012) primary care providers are not consulted when their patients are hospitalized and usually have no input on the plan of care. This is unfortunate because many patients and caregivers have long established trusted relationships with their personal care physicians. A disconnect between inpatient and outpatient care not only puts patient safety risk, it also wastes valuable healthcare provider time (LaMantia et al., 2014). One caregiver in this study had a strong relationship with this patient's primary care physician and when she could not get her questions answered at the hospital, she asked him to come to the hospital, review the patient's medical record, and explain what was happening. The primary care physician visited the patient and caregiver in the hospital and requested a meeting that afternoon with the hospitalist, social worker, and the caregiver. Although this was very helpful to all parties, this level of collaboration is rare. The hospitalist model has increased efficient use of physician resources at the expense of communication and care coordination between inpatient and outpatient healthcare providers (Pham et al., 2008).

Consistent with the current study's findings, communication failures across care settings contribute to confusion about which medications to continue after hospital discharge (Harris et al., 2013). Patients and caregivers have emphasized the need for timely and thorough communication among the hospital staff, the primary care provider, and community pharmacist (Knight et al., 2013). A hospitalist-led initiative used an electronic communication form to improve the transfer of patient discharge information decreased the number of incomplete outpatient workups and increased the number of patients with timely follow up (Balaban, Weissman, Samuel, & Woolhandler, 2008). Purposeful, meaningful communication is vital to patient safety and effective collaboration for patients with dementia and their caregivers (Deeks et al., 2015).

Managing Medications

Caregivers in this study had developed carefully orchestrated medication regimens that promoted optimum cognitive functioning while minimizing side effects. Caregivers expressed frustration when healthcare providers did not adjust their care to accommodate patient routines or home medication schedules necessary to manage patient behaviors. A similar finding was noted in a study of hospitalized seniors who noted that healthcare providers did not acknowledge patient routines or previous management (Dilworth et al., 2012). Lack of attention to needed medications was particularly stressful for caregivers in this study who were concerned about the consequences of missed medications and the implications for patient safety. Timely medication management is a key element of preventing and responding to behavioral symptoms of dementia

(Ostaszkiewicz, Lakhan, O'Connell, & Hawkins, 2015). Research literature confirms that dementia caregivers face challenges in managing medications including complex regimens involving multiple medications, behavioral problems, and lack of information and support (Gillespie, Mullan, & Harrison, 2014).

Positive patient outcomes depend on adherence to prescribed medications (Knight et al., 2013). Caregivers in this study emphasized the importance and helpfulness of having written discharge instructions and a current medication list. The process of medication reconciliation for error prevention is a topic of much research. Multiple studies revealed that between 10% and 71% of patients have at least one medication record discrepancy upon admission, during hospitalization, or at discharge (Tam et al., 2005; Tjia et al., 2009; Vira, Colquhoun, & Etchells, 2006; Wong et al., 2008). One caregiver described a situation in which she was not sure she was going to be able to handle a complex drug dosing regimen. Self-efficacy, health literacy, and cognitive functioning are significant predictors of patient understanding and execution of the discharge instructions (Coleman et al., 2013). New models of care have been proposed to improve medication management after hospital discharge. One pharmacist-led collaborative model demonstrated a significant reduction in 30-day readmissions after hospital discharge that was most effective for older adults (Kirkham, Clark, Paynter, Lewis, & Duncan, 2014). Coordinating among multiple prescribers is a challenge and studies have called for increased involvement of pharmacists in care transitions (Deeks et al., 2015).

Preparing for Discharge

Lack of discharge preparedness has been implicated as a cause of the higher readmission rates seen in seniors (Jencks et al., 2009). Family caregivers are commonly unaware of discharge plans and are rarely engaged in communication to prepare for discharge (Fitzgerald, Bauer, Koch, & King, 2011). Many interventions designed to improve high rehospitalization rates are focused on improved discharge processes that include teaching on signs and symptoms to watch for and report, who to call with questions, and timely follow up care.

Caregivers in this study acknowledged the time constraints of hospital nurses who often did not have time to answer questions, provide discharge teaching, or coordinate care with other healthcare providers. The quality of discharge teaching is a significant predictor of perceived discharge readiness (Weiss et al., 2007) but nurses may not have sufficient time for discharge-related activities because of health system constraints and managed care requirements for timely discharges (Bobay et al., 2010; Nosbusch, Weiss, & Bobay, 2011). Education techniques such as the teach-back method has been used to confirm understanding of discharge teaching but require a time commitment by healthcare providers (Kornburger, Gibson, Sadowski, Maletta, & Klingbeil, 2013).

Discharge planning has been identified by nurses as an area of nursing care often left undone as nurses prioritize their daily tasks and overall workload (Kalisch, 2006). A systematic review of missed care reveals that three of the five categories of care most often left unfinished are vital to safe and effective discharge transitions: education, care coordination and discharge planning, and care planning (Jones, Hamilton, & Murry, 2015). Checklists have been identified as a useful strategy to prevent errors, such as missed care, but should be used with caution as checklists can negatively influence the nurses' ability to recognize and respond to situations not accounted for on the checklist (Hales & Pronovost, 2006).

Recovering at home

A decline in functional status is common in hospitalized seniors (Covinsky et al., 2003) and puts seniors at risk for adverse outcomes including falls, readmissions, and decreased ability to complete activities of daily living (Boltz et al., 2014). Caregivers in this study were passionate about receiving therapy services which they viewed as a proactive approach to improve patients' quality of life and delay institutionalization for as long as possible. Research supports these beliefs and studies have demonstrated the effectiveness of exercise and therapy interventions in delaying functional decline (McLaren, LaMantia, & Callahan, 2013).

Caregivers who called healthcare providers with questions or for guidance had difficulty obtaining assistance. This is consistent with the experiences of seniors readmitted to the hospital within 30 days of discharge who identified inadequate discharge preparation and communication issues as key factors in their inability to remain at home after hospital discharge (Slatyer et al., 2013). The caregivers in this study had positive relationships with outpatient healthcare providers and turned to them for information and support after discharge. A similar theme emerged in an exploration of becoming a new family caregiver during the transition from hospital to home. In that study, caregivers sought information outside the hospital setting from trusted people who knew the patient (Plank, Mazzoni, & Cavada, 2012).

LIMITATIONS

Several limitations must be considered when interpreting the study findings.

Methodology

First, consistent with critical incident technique, the data collected was based on family caregiver recollections of hospital discharge interactions with healthcare providers. These recollections were influenced by the caregivers' perceptions and accumulated experiences but there is no way to know what actually happened during these interactions. It is possible that caregivers who had positive discharge experiences may have believed their experience was routine and that they had nothing of interest to share about the discharge process. Caregivers with especially negative experiences may have felt compelled to share their story to advocate for changes that would help others in similar situations in the future.

Family caregivers may not be aware of all hospital discharge transition activities undertaken by healthcare providers. Family caregivers were asked to report on incidents they deemed significant and may have failed to recognize the significance of events that may have had a critical influence on the outcome but were not recognized as important.

For example, it is possible that healthcare providers attempted to engage caregivers in discharge planning but their efforts were not recognized as such by family caregivers.

Sample

The sample consisted of all white, all female caregivers and it is likely that male caregivers and diverse ethnic or cultural group members would have different experiences and perceptions. All except one were experienced caregivers and had strong ties to the caregiving community, participating in and leading caregiver workshops, respite programs, and support groups. The caregivers were educated and knowledgeable and drew on a number of past hospitalization experiences even beyond the two year point. The previous discharges may have informed the more recent discharge experience, possibly through anticipatory anxiety resulting in hypervigilance that served to confirm negative expectations. Some of the hospitalizations occurred in the distant past and accurate recall may have been an issue. Further, these savvy caregivers may have had higher expectations of care than typical caregivers and may have been more aware of gaps in care. Finally, healthcare providers may have perceived these caregivers as already capable and knowledgeable and not in need of information or support.

Analysis

Data were analyzed using an inductive approach based on a social constructionist perspective in which the researcher's background and experience contributed to the results. Alternative constructions are possible.

IMPLICATIONS

The issues identified by family caregivers of persons with dementia were consistent with similar research reported in the literature. This section will address how study findings may inform practice, education, and research in order to improve patient care.

Practice

The critical incidents described in this study provide valuable insights for healthcare providers working to improve the patient and family experience of care across the care continuum. Healthcare providers are better prepared to establish a collaborative therapeutic relationship when they reflect on their biases and assumptions about persons with dementia and their caregivers. Several of the issues raised by the caregivers in this study are addressed by strategies identified by Naylor and colleagues (2007) as important to meet the special needs of hospitalized elders with dementia. These strategies include recognizing and managing dementia and the acute illness, individualizing interventions to address patient and caregiver needs, conducting medication reviews, and using clinical guidelines to ease the transition from hospital to home. Resources such as the “try this” guide on recognizing dementia (Maslow & Mezey, 2008) can be incorporated into the patient care workflow to ensure healthcare providers are aware of patients who have dementia.

Healthcare providers must make patient and caregiver engagement a priority and apply the practices known to improve transitions of care in their everyday work. There is much to learn from pediatrics in terms of respecting the dignity and autonomy of patients who cannot make their own healthcare decisions. Pediatric providers turn to parents when key healthcare decisions are made while considering the expressions and preferences of the child undergoing treatment. Similarly, it is vital that healthcare providers identify family caregivers of persons with dementia who can confirm the patient's baseline functioning and contribute valuable information to the patient's discharge plan.

Patient and caregiver education, discharge planning, and care coordination are nursing activities that take time. If the very tasks most helpful in ensuring a smooth discharge are the same tasks that are most often postponed or missed entirely, then it is no wonder that hospital to home transitions are problematic. The findings in this study emphasize the importance of discharge as an interprofessional activity. In addition to physicians, nurses, social workers, and therapists, the billing or financial staff can assist caregivers with insurance coverage especially understanding eligibility criteria for services and coverage limitations. Pharmacists are a trusted source of medical information and support caregivers with medication management services for caregivers such as daily unit-dose packaging to simplify medication administration at home.

Healthcare providers can collaborate with quality improvement experts, such as industrial engineers, to address the human factors and systems barriers to well-coordinated discharge processes. Quality improvement strategies such as process mapping and workflow redesign can result in highly reliable discharge process and lead to efficiencies that save providers valuable time.

Education

The study findings have important implications for educators in academia and in healthcare organizations. Interprofessional education addressing person-centered care, communication, teamwork, and safety practices for effective care transitions has the potential to improve healthcare processes through role clarification and shared understanding of the unique contribution of each member of the healthcare team. Transitions theory provides a useful framework for students of all disciplines to better understand the transition process, the roles and relationships among healthcare providers, patients, and caregivers, and how the therapeutic interventions provided by healthcare team members positively influence patient and caregiver outcomes. Lack of knowledge among healthcare providers on how to best work with persons with dementia is all too common. With the aging population and increasing incidence of dementia, healthcare education curricula and continuing education must focus on person-centered approaches to dementia and aging care so that healthcare providers can effectively tailor interventions to patients and families. This education must include practical information on recognizing dementia and preferred strategies for working persons with dementia so that healthcare providers can provide the most effective interventions when needed.

Research shows that information alone is not enough to change practice. Innovative education strategies can help learners consider how new information can be incorporated into daily work. Healthcare providers would benefit from education on care transitions and family caregiver support. Teaching strategies such as “fast-forward rounds" to help students apply transitional care concepts as they learn to individualize discharge interventions (Ouchida, LoFaso, Capello, Ramsaroop, & Reid, 2009). This multimodal educational intervention, developed for medical students, consists of two 90-minute modules that include lecture, interactive video, small group discussions and team-based learning to increase awareness of the key components of transitional care. With an emphasis on functional assessment, students learn to identify patients at risk for poor discharge outcomes and discuss which strategies are likely to be most effective and why.

Providers would benefit from an improved understanding of the elements of discharge interventions that family caregivers deem helpful, factors that contribute to positive or negative patient and family caregiver experiences, and action steps to promote positive patient and family caregiver perceptions (Rademacher, Simpson, & Marcdante, 2010). Successful care collaboration among healthcare team members focuses on addressing risk factors and supporting patients and family caregivers in overcoming barriers to successful recovery. Interprofessional education using case studies of optimum and poorly executed care transitions can help students learn "where caregivers are coming from" and nurture a person-centered orientation. Healthcare providers would also benefit from focused education on communication skills that shape patient and family perceptions of care. When complaints are viewed as indicators of unmet needs instead of criticism or judgment, healthcare providers are able to respond compassionately to caregiver concerns and focus on solutions.

Research

More research is needed on several aspects of hospital to home transitional care for vulnerable populations. Some family caregivers of seniors with dementia are at increased risk for complicated hospital to home transitions such as those with low health literacy, language barriers, limited socioeconomic means, and rural caregivers. Also at high risk caregivers in the "sandwich generation" who are caring for aging parents and children at home, new or inexperienced caregivers, and isolated patients who don't have a caregiver. Additional work with these groups would shed more light on how to design discharge interventions that are flexible enough to meet the needs of diverse populations. The participants in this study were all female and a similar study of all male caregivers may yield important insights on gender differences in caregiving.

Areas of research interest also include studies on patient and family caregiver engagement. Increased involvement of family caregivers in the hospital discharge process is vital and more information is needed on effective engagement including the best way to communicate in a busy hospital environment. The Patient-Centered Outcomes Research Institute has funded over 30 transitional care research projects to date, many for special populations including medically-fragile children and their families. Research on how family engagement is systematized in pediatric care delivery may yield important insights in how healthcare providers can "hardwire" family engagement into the workflow for vulnerable seniors, especially those with dementia.

More work is needed on the phenomena of missed care. Explorations of how discharge-related activities are prioritized by healthcare providers would be useful to inform interventions that prevent missed care. Improvement science research is an important vehicle for not only accelerating the pace of improvement in healthcare organizations but also identifying and implementing the strategies needed to make lasting changes in practice.

Finally, more research is needed with hospital nurses. The responsibility for discharging patients from the hospital belongs with the nurse and more information is needed to understand how nurses coordinate care, develop discharge plans, and provide discharge teaching to patients and families. Health information technology research evaluating patient safety during transitions of care may inform interventions to improve communication among patients, families, and inpatient and outpatient healthcare providers The caregivers in this study were experienced and had developed strategies for navigating the healthcare system. Research with nurses who are also family caregivers may yield valuable information on how healthcare industry “insiders” cope with caregiving challenges and provide insight into how to best support family caregivers.

Policy

There are several implications for health policy. Some researchers have called for the development of payment models that support transitional care. (Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011). Current reimbursement models are being tested in demonstration or pilot projects such as bundled payment initiatives where hospitals are responsible for and receive additional funds to cover patients' post-acute care needs. Accountable care organizations allow for shared cost savings when healthcare providers in a community collaborate to decrease preventable complications and avoid costly rehospitalizations.

Caregivers in this study had strong relationships with community healthcare providers. New models of care such as patient-centered medical homes are beginning to align financial incentives with effective care coordination. This ensures that health care providers are rewarded for well-coordinated transitions of care and are at financial risk when patients with high healthcare costs, such as persons with dementia, are rehospitalized. Finally, family caregivers need more practical support including respite services and reliable, affordable assistance at home (Kripalani et al., 2013) and more funding is needed for programs that delay costly institutional care.

Summary

When a senior with dementia is hospitalized, the family caregiver is the consistent voice for patient needs from the time of admission to discharge. The themes in this study emphasize the critical importance of the healthcare provider relationships with patients and family caregivers. Fragmentation is a property of the current healthcare system and increased involvement of family caregivers in hospital discharge processes will go a long way towards ensuring safe and well-coordinated hospital to home discharge transitions.

Appendix A: Literature Review Supplement

- Codebook
- Codesheet
- Phase I: Excluded Studies
- Phase II: Excluded Studies

Appendix A: Literature Review Supplmenent

CODEBOOK AND DECISION LOG: Hospital to Home Transitions of Older Adults from the Caregiver Perspective

Item	Rationale
1. Study ID Number	For tracking purposes – Funding source, potential source of bias
2. Reference	Paste directly from End Note in APA format. Because this is not a meta-analysis, I don't need to track reference components separately on the codesheet. When I enter the items on the Excel spreadsheet, I will enter the year separately for sorting purposes. There are some authors with multiple studies.
3. Country	For this paper, I want to distinguish US from international studies. The research will be a critical incident study with the purpose of developing a practical and useful set of useful staff behaviors. Because
4. Theoretical framework	List the framework or concepts of focus in the study
5. Inclusion criteria	Focus of this study is Transitions theory – transitions type situational hospital to home and simultaneous transition of health – illness i. Target of study is adults over age 65 - it is OK to include studies if the sample is defined as Medicare beneficiaries as long as the reported average age of the sample is over 65 and the stated focus is "older adults." It is possible that early retirees may be included when the Medicare payer source is used to identify subjects because some beneficiaries begin receiving Medicare at age 62. ii. The involvement of caregivers is central to study, even if caregivers are not specifically described as a target of intervention. iii. Transition situation is acute care hospital to home setting iv. Published in a peer-reviewed journal
6. Exclusion criteria	i. Transition is to a setting other than an independent-living, residential community setting ii. Transition is from a setting other than an acute care hospital iii. Record the rationale for exclusion
7. Aim / Purpose:	Describe
8. Design	Describe – save qualitative studies for context or integrative review later. Will complete a codesheet and quality scoring for the experimental research. This is a quality scoring item, not randomization. 12/22/2013 Revision plan note: Decided to include various types of research in this literature review

Creation Date: 11/1/13; Revision dates: 12/22/2013, 12/29/13, 2/13/14

CODEBOOK AND DECISION LOG: Hospital to Home Transitions of Older Adults from the Caregiver Perspective

Item	Rationale
	Rationale: To get a clearer picture of the literature gaps. 12/25/14: Revision plan – changed from Jadad scoring for quality to Brown (1991) Rationale: To get a clearer picture of study quality, blinding is not practical in some intervention studies, and all the quality scores were coming out the same. There is more diversity in quality scores using a revised method from Brown. Changes made – simplified the scoring to add up to 20 – no "bonus points"
9. Theoretical Framework	List theoretical framework and citation if specified. For example: stress process (Lazarus & Folkman, 1996) If no theoretical framework is specified, list the concepts of interest so that a framework can be inferred.
10. Sample	Provide a brief description of sample, population, recruitment – this is a quality scoring item
11. Transition Properties	Describe any of the following addressed, if not addressed, mark NA on codesheet a. Awareness b. Engagement c. Change and difference d. Transition Time Span - Longitudinal studies capture transition process over time. Note if repeated measures, indicate time points for measurement e. Critical Points and Events **(DISSERTATION FOCUS)**
12. Nature of Transition: Health Illness	The purpose of this section is to identify any patient or caregiver factors that may influence the health illness transition – also known in transition theory as facilitators and inhibitors: a. Patient Factors 1. Average age: _____ 2. Age Range : _____ to ______

Item	Rationale
	3. Final sample: _________ 4. Race / ethnicity 5. Culture / beliefs / Attitudes 6. SES 7. Education level 8. Cognitive impairment? ______________________ 9. Diagnosis Features i. Acute medical __________________ ii. Acute surgical __________________ iii. Exacerbation of chronic illness: _________________ iv. Sudden illness: _________________ v. Critical illness? Days in ICU: __________________ vi. Life-limiting illness? Terminal condition: _____________________ 10. Health literacy? b. Caregiver factors 1. Relationship to pt (spouse, adult child, other – ie family friend) 2. Gender 3. Age

Item	Rationale
	4. Health problems 5. Caregiver ability 6. New caregiver 7. Employment 8. Race / ethnicity 9. Culture / beliefs / Attitudes 10. SES 11. Other
13. Nursing Therapeutics	Circle all that apply, make notes to describe unique features of interventions. a. Is there a description of “usual care” for the comparison group? b. Pre-discharge assessment c. Pre-discharge planning d. Pre-discharge preparation 1. Educational interventions 2. Making follow up appointments 3. Ordering equipment / supplies 4. Referral for home health / other home support

Item	Rationale
	e. Communication / information transfer / coordination of care f. Post-discharge support 1. Telephone follow-up 2. Home visit 3. Follow-up appointment g. Combination interventions h. Collaboration among disciplines (circle all that apply) 1. RNs / Case Managers / Advanced Practice Nurse 2. Physicians 3. Social Work / Case Managers / Discharge Planners 4. Other: _______________________ Intervention notes: note whether intervention was delivered face-to-face, one-on-one with pt/caregiver, or by audiovisual or printed materials. Note duration, time spent if specified. Observe descriptions of usual care – quality scoring item.
14. Patterns of Response	Check all that apply, note instruments used and time frame of measurement. a. Process Indicators 1. Coping 2. Confidence 3. Perceived readiness for discharge 4. Feeling connected

<table>
<tr><th>Item</th><th>Rationale</th></tr>
<tr><td></td><td>5. Interacting / Engaged / Involved
6. Located / being situated
7. Other
b. Outcome indicators - Transitions theory – role related
1. Sense of mastery
2. Caregiver identity
3. Roles
c. System / Utilization measures
1. Readmissions
a. All cause readmissions
b. Related
c. Unplanned
2. ER visits
3. Hospital – index length of stay
4. Other – describe</td></tr>
<tr><td>15. Quality Scoring</td><td>Based on modification of Brown (1991) methodological quality for meta-analysis. Rationale: Jadad score not specific enough, blinding not practical in some settings; changed slightly to streamline scoring – eliminate use of bonus points but included same domains of scoring. Total score for revised scoring method = 20. Excel formula calculates percent of total score obtained.
<table>
<tr><td>Study Design</td><td></td></tr>
<tr><td>Randomized control trial = 3</td><td></td></tr>
<tr><td>Pilot / quasi-experimental =2</td><td></td></tr>
<tr><td>Pre-test /post-test , non equivalent groups = 1</td><td></td></tr>
<tr><td>0= not specified</td><td></td></tr>
<tr><td>Sample</td><td></td></tr>
<tr><td>Random population sample = 3</td><td></td></tr>
<tr><td>Randomized w/ inadequate description, or not random sample but random group assignment = 2</td><td></td></tr>
</table></td></tr>
</table>

Appendix A: Literature Review Supplmenent

CODEBOOK AND DECISION LOG: Hospital to Home Transitions of Older Adults from the Caregiver Perspective

Item	Rationale	
	Convenience sample described = 1	
	Not described = 0	
	Specification of illness or condition	
	Replicable inclusion, exclusion criteria = 3	
	Inclusion criteria specified, no description of excluded cases = 2	
	Diagnosis only = 1	
	Not specified = 0	
	Description of intervention	
	Completely replicable , description of usual care = 3	
	Incomplete description (no description of frequency, duration, “dose”) = 2	
	Intervention inferred from text but not described = 1	
	Not specified = 0	
	Outcome Construct	
	Replicable = 2	
	Vague definition = 1	
	Not specified = 0	
	Outcome Measure	
	Objective, direct, and longitudinal (at least 2 time points) = 4	
	Immediate / directly measured = 3	
	Objective indirect = 2	
	Subjective measures / self report = 1	
	Not specified = 0	
	Data Analysis	
	Intent to Treat methods specified = 2	
	Total Quality Score	

Creation Date: 11/1/13; Revision dates: 12/22/2013, 12/29/13, 2/13/14

Appendix A: Literature Review Supplement
Codesheet: Hospital to Home Transitions of Seniors with Dementia from the Caregiver Perspective

1) Study ID Number: ______________________________________
2) Reference
3) Country
4) Funding source
5) **Inclusion criteria: Transition Type - Situational - Hospital to home**
    i. Target of study is adults over age 65
    ii. Caregivers are central to study if not target of intervention
    iii. Transition situation is acute care hospital to home setting
6) **Exclusion Criteria: Transition Patterns – Unrelated, Other Transition Types**
    i. Transition is to a setting other than an independent-living, residential community setting (ALF, SNF, PCH)
    ii. Transition is from a setting other than an acute care hospital (rehab, psych, day hospital)
    iii. Describe rationale for exclusion: ____
7) Aim / Purpose

8) Design * Circle all that apply / describe randomization

RCT Pilot Quasi-Exp

9) Theoretical Framework / Core Concepts

Revision date: 2/13/14 * Denotes quality scoring item

10) Sample * Description / Population / Recruitment

11) **Transition Theory Properties**

Describe any of the following addressed, if not addressed, mark NA

- a. Awareness
- b. Engagement
- c. Change and difference
- d. Transition Time Span *
  - i. Repeated measures?
  - ii. Measurement time points:
    1. 7 days
    2. 14 days
    3. 30 days
    4. 60 days
    5. 90 days
    6. 6 months (180 days)
    7. 1 year
    8. Other
- e. Critical Points and Events

12) **Transitions Theory: Nature of Transition Health – Illness**

- a. Patient Factors
  1. Average age: _____
  2. Age Range : _____ to ______
  3. Final sample: _________

        4. Race / ethnicity
        5. Culture / beliefs / Attitudes
        6. SES
        7. Education level
        8. Cognitive impairment? ______________________
        9. Diagnosis Features
            i. Acute medical __________________
            ii. Acute surgical __________________
            iii. Exacerbation of chronic illness: _________________
            iv. Sudden illness: _________________
            v. Critical illness? Days in ICU: __________________
            vi. Life-limiting illness? Terminal condition: _____________________
        10. Health literacy?
    b. Caregiver factors
        1. Relationship to pt
        2. Gender
        3. Age
        4. Health problems
        5. Caregiver ability
        6. New caregiver
        7. Employment
        8. Race / ethnicity
        9. Culture / beliefs / Attitudes
        10. SES
        11. Other

13) Transitions theory: Nursing Therapeutics (Interventions * - Circle all that apply)

a. Is there a description of “usual care” for the comparison group?

b. Pre-discharge assessment

c. Pre-discharge planning

d. Pre-discharge preparation

    1. Educational interventions
    2. Making follow up appointments
    3. Ordering equipment / supplies
    4. Referral for home health / other home support

e. Communication / information transfer / coordination of care

f. Post-discharge support

    1. Telephone follow-up
    2. Home visit
    3. Follow-up appointment

g. Combination interventions

h. Collaboration among disciplines (circle all that apply)

    1. RNs / Case Managers / Advanced Practice Nurse
    2. Physicians
    3. Social Work / Case Managers / Discharge Planners
    4. Other: ______________________

14) Transitions Theory: Patterns of Response (Description of Outcome Constructs and Measures*)

a. Process Indicators / Instruments / Reliabilities

Appendix A: Literature Review Supplement

Codesheet: Hospital to Home Transitions of Seniors with Dementia from the Caregiver Perspective

Concept	**Instrument / α**	**IG - Time 1/2/3**	**CG / Time 1/2/3**	**Change scores**
1. Coping				
2. Confidence				
3. Perceived readiness for DC				
4. Feeling connected				
5. Involvement / Engagement				
6. Located / being situated				
7. Other:				

Outcome indicators

1. Sense of mastery – Role related?
2. Caregiver identity – Role acquisition?
3. Other?

b. System / Utilization measures – (Proxy for ability to manage self-care effectively)

Concept	**IG Time 1/2 /3**	**CG Time 1/ 2 /3**	**Change scores**
1. Readmission			

a. All cause readmission b. Related c. Unplanned			
2. ER visits			
3. Hospital – index length of stay			
4. Other:			

15. **Quality Scoring**

Study Design	
Randomized control trial = 3	
Pilot / quasi-experimental =2	
Pre-test /post-test , non equivalent groups = 1	
0= not specified	
Sample	
Random population sample = 3	
Randomized w/ inadequate description, or not random	
Convenience sample described = 1	
Not described = 0	
Specification of illness or condition	
Replicable inclusion, exclusion criteria = 3	
Inclusion criteria specified, no description of excluded	
Diagnosis only = 1	
Not specified = 0	
Description of intervention	
Completely replicable , description of usual care = 3	
Incomplete description (no description of frequency,	
Intervention inferred from text but not described = 1	
Not specified = 0	
Outcome Construct	

Replicable = 2	
Vague definition = 1	
Not specified = 0	
Outcome Measure	
Objective, direct, and longitudinal (at least 2 time points)	
Immediate / directly measured = 3	
Objective indirect = 2	
Subjective measures / self report = 1	
Not specified = 0	
Data Analysis	
Intent to Treat methods specified = 2	
Total Quality Score	

Maximum score = 20

Appendix A: Literature Review Supplement

Phase I Hospital to Home Literature Review Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
1. Anderson, C., Deepak, B. V., Amoateng-Adjepong, Y., & Zarich, S. (2005). Benefits of comprehensive inpatient education and discharge planning combined with outpatient support in elderly patients with congestive heart failure. Congestive Heart Failure 11(6), 315-321.	Caregivers not included in study, though patient's social support status is mentioned.
2. Anderson, J. A., Petersen, N. J., Kistner, C., Soltero, E. R., & Willson, P. (2006). Determining predictors of delayed recovery and the need for transitional cardiac rehabilitation after cardiac surgery. Journal of the American Academy of Nurse Practitioners, 18(8), 386-392.	Transition not hospital to home (cardiac rehab); not focused on seniors, study age range 31-89, mean age 63.
3. Bixby, M. B., Konick-McMahon, J., & McKenna, C. G. (2000). Applying the transitional care model to elderly patients with heart failure. Journal of Cardiovascular Nursing, 14(3), 53-63.	Not research, case exemplars.
4. Bobay, K. L., Jerofke, T. A., Weiss, M. E., & Yakusheva, O. (2010). Age-related differences in perception of quality of discharge teaching and readiness for hospital discharge. Geriatric Nursing (New York, N.Y.), 31(3), 178-187. doi: 10.1016/j.gerinurse.2010.03.005	Caregivers not a focus of study, only completed data if patient unable (18 caregivers of /1892 subjects).
5. Boyd, C. M., Landefeld, C. S., Counsell, S. R., Palmer, R. M., Fortinsky, R. H., Kresevic, D., . . . Covinsky, K. E. (2008). Recovery of activities of daily living in older adults after hospitalization for acute medical illness. Journal of the American Geriatrics Society, 56(12), 2171-2179. doi: 10.1111/j.1532-5415.2008.02023.x	Not focused on hospital discharge process; focus is on recovery of ADLs.
6. Cho, E. (2007). The effects of nonprofessional caregivers on the rehospitalization of elderly recipients in home healthcare. ANS. Advances In Nursing Science, 30(3), E1-E12.	Not focused on hospital discharge process; focus is on risk of readmission in elderly home health patients.
7. Counsell, S. R., Holder, C. M., Liebenauer, L. L., Palmer, R. M., Fortinsky, R. H., Kresevic, D. M., . . . Landefeld, C. S. (2000). Effects of a multicomponent intervention on functional outcomes and process of care in hospitalized older	Caregivers not mentioned

Appendix A: Literature Review Supplement
Phase I Hospital to Home Literature Review Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
patients: a randomized controlled trial of Acute Care for Elders (ACE) in a community hospital. Journal of the American Geriatrics Society, 48(12), 1572-1581.	
8. Dougherty, M. (2010). Assessment of patient and family needs during an inpatient oncology experience. Clinical Journal of Oncology Nursing, 14(3), 301-306.	Not focused on seniors 65+, mean age 53 (SD 14.12); target pop. was oncology patients > age 18.
9. Eldredge, D. H., Nail, L. M., Maziarz, R. T., Hansen, L. K., Ewing, D., & Archbold, P. G. (2006). Explaining family caregiver role strain following autologous blood and marrow transplantation. Journal of Psychosocial Oncology, 24(3), 53-74.	Not focused on seniors 65+, mean age 52; target population was bone marrow transplant patients.
10. Giarelli, E., McCorkle, R., & Monturo, C. (2003). Caring for a Spouse After Prostate Surgery: The Preparedness Needs of Wives. Journal of Family Nursing, 9(4), 453-485. doi: 10.1177/1074840703258317	Not focused on seniors 65+, age range 32-73, mean age 53.5; target population was wives of prostate surgery patients.
11. Grant, M., Cooke, L., Williams, A. C., Bhatia, S., Popplewell, L., Uman, G., & Forman, S. (2012). Functional status and health-related quality of life among allogeneic transplant patients at hospital discharge: a comparison of sociodemographic, disease, and treatment characteristics. Supportive Care In Cancer: Official Journal Of The Multinational Association Of Supportive Care In Cancer, 20(11), 2697-2704. doi: 10.1007/s00520-012-1389-8	Not focused on seniors 65+, mean age 48.
12. Hendrix, C., & Ray, C. (2006). Informal caregiver training on home care and cancer symptom management prior to hospital discharge: a feasibility study. Oncology Nursing Forum, 33(4), 793-798. doi: 10.1188/06.ONF.793-798	Transition not hospital to home (extended care rehab to home)
13. Holland, D. E., Harris, M. R., Pankratz, V. S., Closson, D. C., Matt-Hensrud, N. N., & Severson, M. A. (2003). Prospective evaluation of a screen	Not focused on seniors 65+, age range 21-101, mean age 62.6.

Appendix A: Literature Review Supplement
Phase I Hospital to Home Literature Review Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
for complex discharge planning in hospitalized adults. Journal of the American Geriatrics Society, 51(5), 678-682.	
14. King, R. B., Carlson, C. E., Shade-Zeldow, Y., Bares, K. K., Roth, E. J., & Heinemann, A. W. (2001). Transition to home care after stroke: depression, physical health, and adaptive processes in support persons. Research In Nursing & Health, 24(4), 307-323.	Not focused on seniors 65+, age range 24-85, mean age 60.
15. Levine, C., & Kuerbis, A. (2002). Building alliances between social workers and family caregivers. Journal of Social Work in Long-Term Care, 1(4), 3-17.	Not research; transition not hospital to home (long term care)
16. Li, H., Morrow-Howell, N., & Proctor, E. (2006). Contribution of Secondary Caregivers to Post-Acute Home Care for Elderly Patients. Journal of Social Service Research, 33(1), 39-46. doi: 10.1300/J079v33n01_04	Not focused on hospital discharge process of seniors and their caregivers; this study focuses on support of secondary caregivers.
17. Lipson, A. R., Kelley, C. G., Higgins, P. A., & Daly, B. J. (2006). 'My mother's leaving today?': A pilot study on awareness of discharge date in the chronically critically ill. Medsurg Nursing: Official Journal Of The Academy Of Medical-Surgical Nurses, 15(1), 8-12.	Not focused on seniors 65+, age range 24-83, mean age 62.3, median age 64.0
18. Martin, R. C. G., Brown, R., Puffer, L., Block, S., Callender, G., Quillo, A., . . . McMasters, K. M. (2011). Readmission rates after abdominal surgery: the role of surgeon, primary caregiver, home health, and subacute rehab. Annals Of Surgery, 254(4), 591-597.	Transition not hospital to home (rehab);
19. Mazaleski, A. (2011). Postoperative total joint replacement class for support persons: enhancing patient and family centered care using a quality improvement model. Orthopaedic Nursing / National Association Of Orthopaedic Nurses, 30(6), 361-364. doi:	Not focused on hospital discharge process of seniors and their caregivers; this study focuses on improving a joint replacement class

Appendix A: Literature Review Supplement
Phase I Hospital to Home Literature Review Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
10.1097/NOR.0b013e31823710b5	for pre-surgical patients and their families.
20. Neff, D. F., E. Madigan, et al. (2003).APN-Directed Transitional Home Care Model: achieving positive outcomes for patients with COPD. Home Healthcare Nurse 21(8): 543-550.	No mention of caregivers; Not specifically focused on the hospital to home transition. This study tested an APN-directed disease management intervention for COPD patients receiving home health services. The length of stay for the index hospitalization was reported, but the interval between hospital discharge and home care was not specified.
21. Nelson, M. M., M. A. Smith, et al. (2008). Declining patient functioning and caregiver burden/health: the Minnesota stroke survey--quality of life after stroke study. The Gerontologist 48(5): 573-583.	Not focused on hospital discharge process of seniors and their caregivers; focused on continuing neurological decline post-stroke
22. Neufeld, S. W., Lysack, C. L., MacNeill, S. E., & Lichtenberg, P. A. (2004). Living Arrangement Decisions at Discharge and Later: Differences in Criteria and Outcomes. Home Health Care Services Quarterly, 23(4), 29-47.	Transition not hospital to home (rehab);
23. Parry, C., Min, S.-J., Chugh, A., Chalmers, S., & Coleman, E. A. (2009). Further application of the care transitions intervention: results of a randomized controlled trial conducted in a fee-for-service setting. Home Health Care Services Quarterly, 28(2-3), 84-99.	Transition not exclusively hospital to home (some patients went to nursing facilities, numbers not reported)
24. Parsons, P. L., & Gifford, C. (2002). Characteristics and outcomes of elderly patients receiving transitional care. Outcomes Management, 6(4), 182-185.	Transition not hospital to home (rehab);

Appendix A: Literature Review Supplement
Phase I Hospital to Home Literature Review Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
25. Popejoy, L. L. (2008). Adult protective services use for older adults at the time of hospital discharge. Journal of Nursing Scholarship, 40(4), 326-332. doi: 10.1111/j.1547-5069.2008.00246.x	Not focused on hospital discharge process of seniors and their caregivers; this study focused on healthcare provider use of Adult Protective Services at the time of discharge.
26. Rose, J. H., Bowman, K. F., & Kresevic, D. (2000). Nurse versus family caregiver perspectives on hospitalized older patients: an exploratory study of agreement at admission and discharge. Health Communication, 12(1), 63-80. doi: 10.1207/S15327027HC1201_04	Not specific to hospital discharge process, focused on differing perceptions between nurses and family caregivers of seniors' health status and needs.
27. Scherbring, M. (2002). Effect of caregiver perception of preparedness on burden in an oncology population. Oncology Nursing Forum, 29(6), E70-E76.	Not focused on seniors 65+, median age 59.
28. Van Pelt, D. C., Schulz, R., Chelluri, L., & Pinsky, M. R. (2010). Patient-specific, time-varying predictors of post-ICU informal caregiver burden: the caregiver outcomes after ICU discharge project. Chest, 137(1), 88-94.	Transition not hospital to home (ICU).
29. Vom Eigen, K. A., Walker, J. D., Edgman-Levitan, S., Cleary, P. D., & Delbanco, T. L. (2000). A comparison of carepartner and patient experiences with hospital care. Families, Systems & Health: The Journal Of Collaborative Family Healthcare, 18(2), 191-203.	Not focused on hospital discharge process of seniors and their caregivers; this study is about patient and caregiver satisfaction with hospital care; Careparnters reported problems with discharge planning (24.6%)and family participation (17.6%).

Appendix A: Literature Review Supplement
Phase I Hospital to Home Literature Review Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
30. Weaver, C., Schiech, L., Held-Warmkessel, J., Kedziera, P., Haney, E., DiLullo, G., . . . Barsevick, A. (2006). Risk for unplanned hospital readmission of patients with cancer: results of a retrospective medical record review. Oncology Nursing Forum, 33(3), E44-E52.	Not focused on seniors 65+, age range 22-87.
31. Wolff, J. L., & Kasper, J. D. (2004). Informal caregiver characteristics and subsequent hospitalization outcomes among recipients of care. Aging Clinical And Experimental Research, 16(4), 307-313.	Not focused on hospital discharge process of seniors and their caregivers.

Appendix A: Literature Review Supplement

Phase II: Dementia Caregiver Interventions Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
1. Aharonoff, G. B., A. Barsky, et al. (2004). "Predictors of discharge to a skilled nursing facility following hip fracture surgery in New York state." Gerontology 50(5): 298-302.	Not DC home
2. Baillie, L., J. Cox, et al. (2012). "Caring for older people with dementia in hospital Part one: challenges." Nursing Older People 24(8): 33-37.	Not research
3. Baillie, L., J. Merritt, et al. (2012). "Caring for older people with dementia in hospital Part two: strategies." Nursing Older People 24(9): 22-26.	Not research
4. Bobay, K. L., T. A. Jerofke, et al. (2010). "Age-related differences in perception of quality of discharge teaching and readiness for hospital discharge." Geriatric Nursing 31(3): 178-187.	Not dementia
5. Happy Bradas, C. M. and L. C. Mion (2011). "Hospitalized Patients with Dementia: The Dilemma of Managing Agitation." Geriatric Nursing 32(6): 455-458.	Not research
6. Bradway, C. and K. B. Hirschman (2008). "Working with families of hospitalized older adults with dementia: caregivers are useful resources and should be part of the care team." The American Journal Of Nursing 108(10): 52-60.	Not research
7. Brindle, N. and J. Holmes (2005). "Capacity and coercion: dilemmas in the discharge of older people with dementia from general hospital settings." Age & Ageing 34(1): 16-20.	Not research
8. Bull, M. J., H. E. Hansen, et al. (2000). "Differences in family caregiver outcomes by their level of involvement in discharge planning." Applied Nursing Research 13(2): 76-82.	Not dementia
9. Bull, M. J., H. E. Hansen, et al. (2000). "Predictors of elder and family caregiver satisfaction with discharge planning." Journal of Cardiovascular Nursing 14(3): 76-87.	Not dementia
10. Buurman, B. M., J. G. Hoogerduijn, et al. (2011). "Geriatric conditions in acutely hospitalized older patients: prevalence and one-year survival and functional decline." Plos One 6(11): e26951-e26951. 20(11), 2697-2704. doi: 10.1007/s00520-012-1389-8	Not hospital discharge
11. Cunningham, C. and C. Archibald (2006). "Supporting people with dementia in acute hospital settings... first in a series of five." Nursing Standard 20(43): 51-55.	Not research
12. Daiello, L. A., R. Gardner, et al. (2014). "Association of	Not hospital

Appendix A: Literature Review Supplement
Phase II: Dementia Caregiver Interventions Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
dementia with early rehospitalization among Medicare beneficiaries." <u>Archives Of Gerontology And Geriatrics</u> 59(1): 162-168.	discharge
13. Dang, S., N. Remon, et al. (2008). "Care coordination assisted by technology for multiethnic caregivers of persons with dementia: a pilot clinical demonstration project on caregiver burden and depression." <u>Journal of Telemedicine & Telecare</u> 14(8): 443-447.	Not hospital discharge
14. Davis, K. K., M. Mintzer, et al. (2012). "Targeted intervention improves knowledge but not self-care or readmissions in heart failure patients with mild cognitive impairment." European Journal Of Heart Failure 14(9): 1041-1049.	Not caregivers
15. Epstein-Lubow, G. and A. T. Fulton (2012). "Post-hospital transitions for individuals with moderate to severe cognitive impairment." Annals of Long Term Care 20(3): 18-24.	Not research
16. Foust J. B., N. Vuckovic, et al. (2012). "Hospital to Home Health Care Transition: Patient, Caregiver, and Clinician Perspectives." <u>Western Journal of Nursing Research</u> 34(2): 194-212.	Not dementia
17. Ghatak, R. (2011). "A Unique Support Model for Dementia Patients and Their Families in a Tertiary Hospital Setting: Description and Preliminary Data." <u>Clinical Gerontologist</u> 34(2): 160-172.	Not hospital discharge process
18. Greysen, S. R., D. Hoi-Cheung, et al. (2014). "'Missing Pieces'-Functional, Social, and Environmental Barriers to Recovery for Vulnerable Older Adults Transitioning from Hospital to Home." <u>Journal Of The American Geriatrics Society</u> 62(8): 1556-1561.	Not dementia
19. Holen, K. A. (2006). "Post-hospital transition to a skilled nursing facility--Compliance, competence, and communication." <u>Journal Of Gerontological Nursing</u> 32(9): 5-9.	Not hospital to home
20. Hunt, N. (2010). "Transforming hospital care." <u>Journal of Dementia Care</u> 18(1): 12-13.	Not research
21. Kangovi, S., F. K. Barg, et al. (2014). "Challenges faced by patients with low socioeconomic status during the post-hospital transition." <u>JGIM: Journal of General Internal Medicine</u> 29(2): 283-289.	Not dementia

Appendix A: Literature Review Supplement
Phase II: Dementia Caregiver Interventions Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
22. Knight, D. A., D. Thompson, et al. (2013). "'Seamless care? Just a list would have helped!' Older people and their carer's experiences of support with medication on discharge home from hospital." Health Expectations 16(3): 277-291.	Not dementia
23. Levy, B., S. Celen-Demirtas, et al. (2014). "Neuropsychological screening as a standard of care during discharge from psychiatric hospitalization: the preliminary psychometrics of the CNS Screen." Psychiatry Research 215(3): 790-796.	Not dementia
24. Marks, L., R. B. Flannery, Jr., et al. (2001). "Placement challenges: implications for long-term care of dementia sufferers." American Journal Of Alzheimer's Disease And Other Dementias 16(5): 285-288.	Not hospital discharge
25. O'Connell, B., A. Gardner, et al. (2007). "Clinical usefulness and feasibility of using Reality Orientation with patients who have dementia in acute care settings." International Journal of Nursing Practice 13(3): 182-192..	Not hospital discharge
26. Palmer, J. L., H. W. Lach, et al. (2014). "The Dementia Friendly Hospital Initiative Education Program for Acute Care Nurses and Staff." Journal of Continuing Education in Nursing 45(9): 416-424.	Not research
27. Park, M., C. Delaney, et al. (2004). "Using a nursing minimum data set with older patients with dementia in an acute care setting." Journal of Advanced Nursing 47(3): 329-339.	Not hospital discharge
28. Pirani, S. S. A. (2010). "Prevention of delay in the patient discharge process: an emphasis on nurses' role." Journal for Nurses in Staff Development 26(4): E1-5.	Not research
29. Popejoy, L. L. (2011). "Complexity of Family Caregiving and Discharge Planning." Journal of Family Nursing 17(1): 61-81.	Not dementia
30. Porock, D., P. Clissett, et al. (2015). "Disruption, control and coping: responses of and to the person with dementia in hospital." Ageing & Society 35(1): 37-63.	Not hospital discharge
31. Pritchard, E. and J. Dewing (2001). "Older people with dementia in acute settings." Nursing Older People 12(10): 21-26.	Not research
32. Rice, S. (2013). "Challenges Faced By The Caregiver and The Geriatric Patient: How Occupational Therapists Ease The	Not research

Appendix A: Literature Review Supplement
Phase II: Dementia Caregiver Interventions Excluded Studies with Rationale

Citation	Exclusion Rationale(s)
Transition Out of Acute Care." Communique 2013(2): 9-16.	
33. Romagnoli, K. M., S. M. Handler, et al. (2013). "Home-care nurses' perceptions of unmet information needs and communication difficulties of older patients in the immediate post-hospital discharge period." BMJ Quality & Safety 22(4): 324-332.	Not dementia
34. Sewter, E., R. Jones, et al. (2014). "Charting carer satisfaction: the hospital experience." Journal of Dementia Care 22(5): 19-21.	Not US
35. Swidler, R. N., T. Seastrum, et al. (2007). "Difficult hospital inpatient discharge decisions: ethical, legal and clinical practice issues." Am J Bioethics 7(3): 23-28.	Not research
36. Thompson, R. (2011). "What works, and what we need to do to improve acute hospital care." Journal of Dementia Care 19(6): 14-15.	Not research
37. Turner, B., J. Fleming, et al. (2007). "A qualitative study of the transition from hospital to home for individuals with acquired brain injury and their family caregivers." Brain Injury 21(11): 1119-1130.	Not seniors
38. Zanjani, F. (2015). "Family carers of people with cognitive impairment who are admitted to hospital experience disruption from their normal routine and use a variety of strategies to cope." Evidence Based Nursing 18(1): 6-6.	Not research

Appendix B : Research Study Documents

- Recruitment flyer
- Support letter template
- Consent for participation in research
- Demographic information sheet
- Interview guide

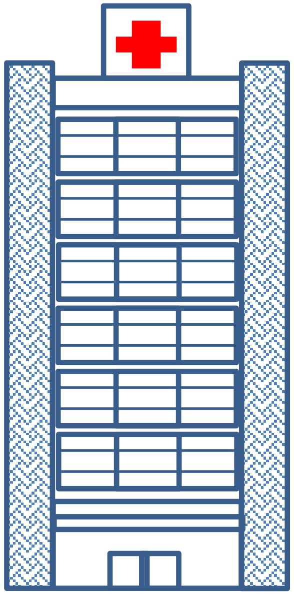
Dementia Caregiver Research - Volunteers Needed

Study: Hospital to Home Discharges of Seniors with Dementia from the Family Caregiver Perspective

What's involved:

An in-person audio recorded interview in a location convenient for you. All information will be confidential. Results will be used to better understand senior and caregiver needs for preparations for going home from the hospital.

Study Details:



- Caregiver must be over 21 and unpaid - may be a family member or close friend
- Senior is at least 65 years or older and spent at least one night in the hospital in the past two years
- Senior has been diagnosed with any type of dementia
- Senior was discharged directly from the hospital to a residence (not a rehabilitation facility or a nursing facility)
- Senior is not currently enrolled in a hospice program

For more information or to schedule an interview, please contact

Ellen Martin, PhD(c), RN, CPHQ, CHPCA
Doctoral candidate, School of Nursing
The University of Texas at Austin
ellenmartin@utexas.edu
512-923-1138

Appendix B: Research Study Documents – Support Letter Template

<<DATE>>

lnstitutional Review Board
University of Texas at Austin
P.O.Box 7426, Mail Code A 3200
Austin, TX 787l3
irbchair@austin.utexas. edu

To whom it may concern:

The purpose of this letter is to grant Ellen Martin, a graduate student at The University of Texas at Austin, permission to conduct recruiting activities for her doctoral dissertation research through <<organization>>. The project, "Hospital to Home Discharge of Seniors with Dementia from the Family Caregiver Perspective" entails recruitment of family caregivers of seniors with dementia who have been hospitalized in the past two years. The <<organization>> was selected because of the services and supports provided to family caregivers including newsletters, caregiver education programs, and caregiver support groups. Ellen is willing to share the research findings with staff who are interested in the results. On behalf of <<organization>>, I support this research effort and grant permission for Ellen Martin to recruit research participants for her study.

<<NAME>>
<<TITLE>>
<<ORGANIZATION>>

Appendix B: Research Study Documents

Demographic Information Sheet

Caregiver's relationship to care recipient	Spouse / Child / Sibling / Other:
Caregiver gender	Female / Male
Care recipient's gender	Female / Male
Onset of caregiving	Sudden / Gradual
Length of caregiving	Less than 3 months / 3 to 6 months 6 months to one year / More than one year: _______ yrs
Prior caregiving experience?	Yes / No / Describe:
Living with care recipient?	Yes / No / Explain:
Employment status of caregiver	Full-time / Part-time / Retired Other:

Appendix B: Research Study Documents – Interview Guide

General Aim: As you know, I am investigating the caregiver perspective of the hospital discharge process for seniors with dementia. I am interested in who at the hospital helped get ___ ready to go home from the hospital. I am also interested in your thoughts on how discharge preparations influenced your confidence and ability to help ___.

Caregiving: As a way of getting started, perhaps you can tell me a little bit about your caregiving experience:

1. How long have you been a caregiver for ___?
2. Did you have prior caregiving experience? If so, what?

Discharge:

3. What were the circumstances leading up to ___ hospitalization? (Planned / unplanned?)
4. How long was ____ in the hospital?
5. When did you first find out _____ was going home?
6. How involved were you able to be in the hospital discharge process?
7. What kinds of things needed to be taken care of before ____ left the hospital?
    a. Decisions to be made?
    b. Services arranged?
8. How did you get this information?
9. Can you give me a specific example of something the hospital staff did to prepare ___ to go home?
10. Did you have any concerns about going home? What were your concerns?
    a. Did you speak with anyone about your concerns?
    b. What did they do?
    c. What was the result?
11. What were the biggest challenges or problems you faced in caring for ____?
12. If there anything you wish had been done differently? How would that have helped?
13. At what point did you feel that you and ___ had “settled” into a routine?
14. Is there anything else you would like to share about the hospital discharge process?

Appendix B: Research Study Documents – Interview Guide

Probe for healthcare provider actions related to:

- Medication management
- Treatments or therapeutic regimen
    - Activity / Rest
    - Diet / Nutrition
    - Wound care
- Monitoring such as signs and symptoms to watch for and report
- Follow-up care / appointments, care coordination
- Other?

References

Abdellah, F. G. (1961). Criterion measures in nursing. *Nursing Research, 10,* 21-26.

Abdellah, F. G., & Levine, E. (1957). Developing a measure of patient and personnel satisfaction with nursing care. *Nursing Research, 5*(3), 100-108.

Ahmed, S., B. Leurent, et al. (2014). Risk factors for incident delirium among older people in acute hospital medical units: a systematic review and meta-analysis. *Age And Ageing 43*(3): 326-333.

Altfeld, S. J., Shier, G. E., Rooney, M., Johnson, T. J., Golden, R. L., Karavolos, K., . . . Perry, A. J. (2012). Effects of an enhanced discharge planning intervention for hospitalized older adults: A randomized trial. *The Gerontologist 53*(3), 430-440.

Alzheimer's Association. (2015). Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia 2015;11*(3): 332+.

American Nurses Association. (2001). *Code of ethics for nurses with interpretive statements*. American Nurses Association: Silver Spring, MD.

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