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Care Transitions: A Mixed Methods Study Using a Complexity Science Lens

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**CARE TRANSITIONS:
A MIXED METHODS STUDY USING A COMPLEXITY SCIENCE LENS**

By

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A DISSERTATION

Presented to the Faculty of
The Graduate College in the University of Nebraska
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Under the Supervision of Karen L. Schumacher, PhD

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Thank you to the principals and family caregivers who took the time to speak with me with attention and focus during a time of great turmoil and fatigue. Your willingness to share your experience made all the difference.

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To my family, who has had great hopes that this would be over soon. Unfortunately, it has only just begun.

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CARE TRANSITIONS:

A MIXED METHODS STUDY USING A COMPLEXITY SCIENCE LENS

Carol Reynolds Geary, Ph.D.

University of Nebraska Medical Center, 2016

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Research studies on care transitions from hospital to nursing home are few and heterogeneous, offering an inadequate characterization to support practice. The purpose of this study was to characterize multiple care transitions among hospitalized older adults with advanced chronic disease who were discharged to a nursing home. This prospective, mixed methods study used multiple case studies with an embedded quantitative strand and multiple sources of information.

Four cases included an index patient (an older hospitalized adult with advanced chronic illness), his or her informal caregiver, if available, and healthcare providers involved in the index patient's care. Two hospitals and two nursing homes participated. Healthcare providers, expert in care transitions within those facilities, were interviewed for facility context.

Care transitions occurred in two contexts: the facilities' organizational context and the patients' ongoing life transitions. While care transitions were time-bounded healthcare provider-centered processes, life transitions were ongoing and principal-centered. Defined care transition processes were complicated. However, dynamic interactions between patients, family caregivers, and healthcare providers occurred in multiple

complex systems. Dynamic interactions within the complex systems were affected by the alignment of the familial approach to patient support with the patient's needs and the availability of a stable core. Symptom distress and quality of life trajectories did not illuminate differences in principal experiences. However, patterns of dynamic interactions were different between patients experiencing unplanned utilization and those who did not.

Fragmented processes and lack of feedback loops were the norm. This fragmentation limited information flow. Simple outcome measures did not reflect the complexity of care transitions. While quality of life measures and symptom distress did reflect the patients' situation at a moment in time, they did little to explain the patient's experience of care transitions.

Implications for practice relate to the complexity within care transitions. Limited information flow due to role fragmentation and lack of feedback loops hamper learning and adaptation both within individual cases and across facilities. Care transitions from hospital to skilled nursing facility occurred within complex systems. As such, future research must consider not only the processes, but also the relationships and dynamic interactions within the systems.

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LIST OF ABBREVIATIONS

APRN	Advanced Practice Registered Nurse
CAS	Complex adaptive system
ER	Emergency room
HCP	Health care provider
LPN	Licensed practical nurse
LTACH	Long term acute care hospital
LTC	Long term care
MD	Medical doctor
NH	Nursing home
NP	Nurse practitioner
OT	Occupational therapist
PA	Physician's assistant
PT	Physical Therapist
QoL	Quality of Life
QUAL	Qualitative dominant portion of the study
Quan	Embedded quantitative portion of the study
RN	Registered nurse

SNF Skilled nursing facility

SW Social work

Chapter 1: Introduction

Background

Transitions have been defined in multiple ways: as a process and an event; as a patient-phenomena and a systems-requirement. Bodies of research addressing each definition use different perspectives, methods, and outcomes. The body of research defining transition as transitional care, referred to as a “set of actions designed to ensure the coordination and continuity of care as patients transfer between locations or different levels of care within the same location”(Coleman, Mahoney, & Parry, 2005b), centers on readmission as the major outcome. The Department of Health and Human Services and several national foundations also use readmission as a prominent outcome. Nursing research on transitions describes a patient-experienced phenomenon and defines transitions as “a multiple concept embracing the elements of process, time span, and perception” (Meleis, 2010). Following such a definition, nursing research focuses on the patient’s experience and response with outcomes such as health status and quality of life (QoL). For this study, **care transitions** were defined as the process of moving from one setting or health care provider (HCP) to another, including planning and coordination. This study addressed care transitions from hospital to nursing home and for 120 days following. **Transitions** are the broader experiences including emotional and mental aspects necessary to accommodate the care transition.

Outcomes related to care transitions in older adults are currently a major concern of providers and policymakers. This concern is based upon astounding systems-based statistics: Medicare readmissions cost the health care system \$17.4 billion in 2004 with 19.6% of patients readmitted within 30 days (Jencks, Williams, & Coleman, 2009). Among older patients discharged from hospital to a skilled nursing facility or inpatient rehabilitation facility, 65.8% of

Medicare and 75.6% of fee-for-service patients experienced between two and three transitions during the first 4 months following discharge (Ma, Coleman, Fish, Lin, & Kramer, 2004).

Research to date has addressed individual components within the complex array of care transitions, yet none has attempted to view care transitions holistically. For example, health care reform, with its change in payment policy, prompted research and intervention development aimed at reducing hospital readmissions. Research on interventions has reported reduced readmission rates based upon changes in communication strategies between hospital and the accepting agency or through changes to the support model when discharged to home, but without report on the patient's experience or outcomes related to clinical management, pain and symptom management, or QoL beyond the tested intervention (Bennett, Coleman, Parry, Bodenheimer, & Chen, 2010; Bowles, Foust, & Naylor, 2003; Bowles et al., 2008; Bowles et al., 2008; Bowles et al., 2009; Brooten et al., 2002; Chugh, Williams, Grigsby, & Coleman, 2009; Coleman et al., 2002; Coleman et al., 2002; Coleman et al., 2004; Coleman, Mahoney, & Parry, 2005a; Coleman, Parry, Chalmers, & Min, 2006; Coleman, Parry, Chalmers, Chugh, & Mahoney, 2007; Dedhia et al., 2009; Greenwald & Jack, 2009; Kripalani, Jackson, Schnipper, & Coleman, 2007; Naylor et al., 2004; Naylor et al., 2007; Naylor, Kurtzman, & Pauly, 2009; Parry, Min, Chugh, Chalmers, & Coleman, 2009).

Further, research on transitions across multiple settings is minimal. Following discharge to a skilled nursing or inpatient rehabilitation facility, 98% of patients experienced at least one transfer to another facility or home in 3 months (Ma et al., 2004). The limited research on transitions in nursing homes can be characterized as qualitative descriptions of patient emotional and psychological adjustment (Andersson, Pettersson, & Sidenvall, 2007; Ellis, 2010), or quantitative descriptions of readmissions (Ma et al., 2004; Mor, Intrator, Feng, & Grabowski, 2010) and preventable readmissions (Gozalo et al., 2011; Intrator, Zinn, & Mor, 2004).

Intervention studies also focused on communication between hospital and nursing home (Hustey & Palmer, 2010; Lester et al., 2009; Lester, Stefanacci, & Chen, 2009). No mixed methods studies were identified. While these studies provided important single perspective insights, they failed to capture the complexities of care transition.

To improve outcomes in care transitions through research, a rich description of the dynamic interplay of factors that influence transitions for older adults with advanced chronic illness is needed. For example, a single transition could conceivably be affected by a confluence of issues such as reimbursement limitations; number and skill level of staff in the nursing home; availability of a caregiver; an active and present medical director; clarity of discharge instructions; clarity of prognosis and treatment goals; use of advance directives; and many exacerbating factors such as infections and falls. This study provided a rich description of each patient and his or her care transition(s). Included were qualitative descriptions of the patients', caregivers' and HCPs' perspectives, with quantitative patient-focused measures (QoL and symptoms) and systems-based measures (ER visits and hospital readmissions). This approach allowed the capture of the complexity of care transition as well as the array of events, both clinical and contextual, that affect transition.

Figure 1 is an original depiction of the patient-specific health care system. The model was based upon complexity science and clinical experience. Local environments create situations for each patient with unique availability, accessibility, and coordination of care. Importantly, the experience of a patient discharged is substantially different depending on the local environment since it determines cultural and social norms, the availability of resources, and the constraints on their use. For this reason, the local environment was depicted in the background as the context of the individual's health care system. Interaction of patient and providers, depicted by overlapping and tangent shapes, are unique to the patient. While this

figure represents one possible configuration, there are possibilities approaching infinity. Adding further complexity, each of the HCPs and institutions provide different products and services under different regulations (shape) and with different responsibilities to the patient (color). Therefore, each HCP's view of the patient is different and incomplete. Only the patient has the perspective of receiving care within his or her health care system.

Statement of the Problem

Current research on care transitions from hospital to nursing home is limited in quantity and scope. As such, current research does not capture the dynamic and complex interaction between key players: patient, caregiver, and HCPs. A rich description of this interaction from multiple perspectives is needed.

Conceptual Framework

Complexity science constitutes the conceptual framework for this study and provides a powerful lens through which to analyze care transitions. Complexity science is the “study of complex adaptive systems – the patterns of relationships within them, how they are sustained, how they self-organize and how outcomes emerge” (Zimmerman, Lindberg, & Plsek, 2008). A **complex adaptive system** (CAS) is a collection of individual agents with freedom to act in ways that are not totally predictable and whose actions are interconnected so that one agent's actions change the context for others (Plsek & Greenhalgh, 2001). Figure 1, as described above, illustrates the CAS of a patient undergoing care transition from hospital to nursing home. This CAS provides the facility-level context for the patient's care transition.

Four key concepts in complexity science are information agents, relationships, self-organization, and emergence. Agents within CAS are processors of information. These **information agents** (agents), whether human, computer, or regulatory system, act within and

with knowledge of the local environment, but with or without their awareness, agents' behaviors affect the larger environment, as well. **Relationships** are the opportunity for exchanging information. **Self-organization** reflects the idea that although structures look planned and behavior looks centrally directed, actually they are not (Paley, 2007). Within the patient's experience of transition, this self-organization occurs in the interpretation, adjustment, and modification of the discharge plan by each of the agents involved. Within CAS, overall behavior is a result of the interactions (relationships) of the individual parts. Because each of the agents (whether human or non-human) is independent of the others and unaware of the total actions of others, these systems cannot be reduced to the sum of their parts. **Emerging** properties that are the product of the system, must be viewed from the perspective of the whole rather than from a single (reductionist) perspective to gain organizational insights (Plsek & Greenhalgh, 2001). One emerging property of systems is outcomes such as QoL and health care utilization. Measuring care in terms of readmission outcomes and only in terms of the input of the discharging hospital fails to acknowledge the importance of the patient, caregiver, and receiving facilities in affecting outcomes.

A middle-range theory on the **relationships** in CAS (Anderson et al., 2005) has been adequately developed to support several studies (Anderson, Issel, & McDaniel Jr, 2003; Colón-Emeric et al., 2006; Forbes-Thompson, Leiker, & Bleich, 2007). This theory represents connectivity, information flow, and cognitive diversity as influencers of self-organization and emergence. **Information flow** is the rate of new information available to the CAS. **Connectivity** is the nature of interconnections between agents. **Cognitive diversity** is the level of diversity within and between cognitive schemas of the agents. For this study, relationships are between the patient, caregivers, and HCPs. Self-organization and emergence are in the management and coordination of care transitions.

Complexity science recognizes this dynamic flow of information across boundaries and the incomplete nature of any one view of care transitions. Therefore, it is not the unidirectional movement of discharge planning and instructional information, but the interaction and emergence of behaviors and outcomes that is critical to understanding care transitions. This connection between Complexity Science and transitions has been described by the Principle Investigator (Geary & Schumacher, 2012). It is a modification of this published framework and the middle range theory on relationships that will serve as the model for this study. (See Figure 2).

The tenets of complexity science have informed study design and methods including the prospective nature of the study, data collection from multiple sources, the incorporation of both qualitative and quantitative measures, and analysis of data using both quantitative and qualitative techniques.

Purpose Statement and Specific Aims

The purpose of this study was to characterize multiple care transitions among hospitalized older adults with advancing chronic disease who are discharged to a nursing home. This phenomenon was viewed through a complexity science lens. A prospective, mixed methods, multiple case study design was used in which quantitative data were embedded in qualitative case studies. Each case was bounded by the index patient's experience of care transitions from hospitalization to 120 days following discharge to skilled nursing care within a nursing home.

The qualitative data explored care transitions in aging, hospitalized adults to describe care transitions. The quantitative data was embedded within the larger qualitative strand to describe the experience of the patient in relation to symptom distress, quality of life (QoL), and

unplanned health care utilization. The research design was embedded, mixed methods, and descriptive. Qualitative data were collected from patients, informal caregivers (caregivers), and HCPs. Quantitative data were collected from patients regarding their experience of symptom distress and the quality of their lives. In addition, medical record review was used to collect qualitative data from HCPs and quantitative data regarding unplanned health care utilization. Using the notation system designed by Morse (1991/2008) (Morse, 1991/2008) this design is represented as: Multiple case study (QUAL + quan) = holistic.

Specific aims were to:

Aim 1. Qualitatively describe care transitions experienced over time by older adults with complex health care needs from the perspectives of patients, caregivers, and health care providers. (Primary)

Aim 2. Quantitatively describe patient symptom distress, quality of life, and selected indicators of unplanned health services utilization (i.e., emergency room, hospital readmissions) over time. (Secondary, embedded)

Aim 3. Better understand patterns in the complexity of care transitions using cross-case comparisons in which each case includes both qualitative patterns and quantitative trajectories of symptoms distress, quality of life, and unplanned health services utilization over time. (Mixed methods merging of qualitative and quantitative results)

This study described care transitions from hospital to nursing home and 120 days following, adding substantially to the body of knowledge related to transitions in hospitalized older adults with advanced chronic illness.

Significance

This study combined mixed methods with a complexity science framework to provide a prospective, dynamic view of a very complex problem: care transitions in elderly patients with advanced chronic illness including all transitions from hospital to nursing home and 120 days following. Transitions between health care settings can be inefficient and costly to payers, providers, and patients in terms of dollars, quality of care, and quality of life (QoL). Nearly 1.4 million patients resided in nursing homes during 2012 (Research Department, American Health Care Association, 2012). In 2010, over 40% of hospitalized patients over age 85 were discharged to a nursing home. Nearly one quarter of hospitalized patients aged 65 – 85 were, as well (Healthcare cost and utilization project (HCUP, 2010). Given these dramatic numbers, it is critical that transitions from hospital to nursing home and beyond be well characterized in order to develop interventions to improve patient and system outcomes.

Health care reform is now certain. Reduced costs are essential. One major cost-reduction initiative is decreasing 30-day readmissions to hospitals. To date, quantitative studies have provided useful information regarding the prevalence of and patient characteristics associated with readmissions. Some studies have included interventions aimed at reducing readmissions. Although successful in reducing readmissions to a degree, many studies fall short of examining the complex factors associated with older adults experiencing advancing chronic illness. Complexity and mixed methods together provided an in-depth exploration of the phenomena of care transitions, including outcomes, in the context of patients', caregivers', and HCPs' perspectives. Results will enhance development of interventions that reduce costs and improve QoL.

Summary

In this study, patients were prospectively followed through a hospital discharge and for 120 days afterward as they experienced care transition from hospital to skilled nursing care within a nursing home and beyond. Using a mixed methods, multiple case study approach with an embedded quantitative strand, this study provided an in-depth description of care transitions from the perspectives of patients, caregivers, and HCPs within the hospital and nursing home.

In doing so, this study provided an innovative view of patients at high risk for adverse outcomes of care transitions such as readmission. This view will support the development of nursing, medical, and multidisciplinary interventions that will improve care and decrease unnecessary utilization. Thus, this research addressed a substantial problem.

Definition of Terms

Care transitions: the process of moving from one setting or HCP to another, including planning and coordination. Care transition is the central phenomenon of this study.

Cognitive diversity: the level of diversity within and between cognitive schemas of the information agents (Anderson et al., 2003). Cognitive diversity enables creativity and problem solving.

Complex adaptive system: a group of agents with freedom to act leading to an inability to predict behavior and whose actions change the context for other agents (Plsek & Greenhalgh, 2001). Health care organizations are considered to be complex adaptive systems (Committee on Quality of Health Care in America / Institute of Medicine, 2001). The hospitals and nursing homes participating in the study will be conceptualized as complex adaptive systems.

Complexity science: the “study of complex adaptive systems – the patterns of relationships within them, how they are sustained, how they self-organize and how outcomes

emerge” (Zimmerman et al., 2008). The study of complexity science has broad reach from health care to physics and the natural sciences. Within this study, the concepts and principles of complexity science are approached from the perspective of the social sciences. It is not anticipated that modeling or simulation will be the product of this research.

Connectivity: the nature of interconnections between agents (Anderson et al., 2003).

Connectivity relates to both the quality and quantity of interactions, including formal meetings, social interactions, and happenstance professional interactions, among others.

Emergence – behaviors and qualities that are determined by the interactions of agents within and across systems (Cilliers, 2000).

Environment - The environment is the background for the patient’s individual health care system. Through local cultural and social norms and availability of resources, the local environment creates situations that the patient will receive care within.

ER visit – Emergency room visits that do not result in a hospitalization are considered unplanned health care utilization for purposes of this study.

Hospital readmission – unplanned hospital admission following hospital discharge. This study will include readmission up to 120 days within unplanned health care utilization.

Informal caregiver (caregiver) – Family members, friends, or neighbors who provide support and assistance over time.

Information agent – exchanges information with other agents and their environment and change their behavior in response to that information. Agents can be human, electronic, or organizations, but are not under central control – even if they appear to be (McDaniel Jr & Driebe, 2001).

Information flow – the rate of information flow through the system. Information flow is affected by the nature and number of connections available as well as the diversity available within the system (Anderson et al., 2003).

Mixed methods study – includes the collection and analysis of both quantitative and qualitative data as well as the integration of the data addressing a single problem (Plano Clark, 2010).

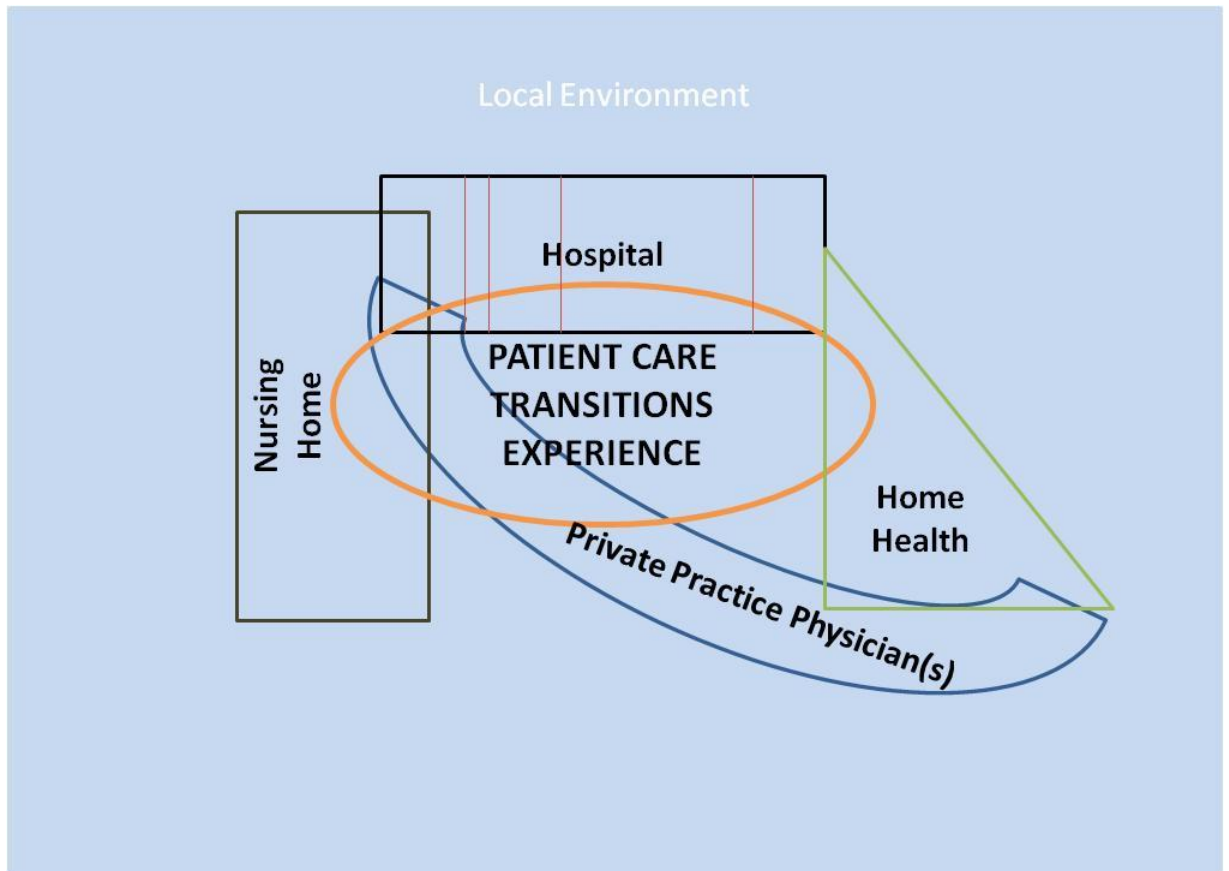
Patient-specific health care system – The complex adaptive system in which the individual patient receives care. The patient-specific health care system includes all HCP's and resources involved in the provision of care.

Relationships: involve dynamic interactions between agents (Cilliers, 2000) and have patterns that shape the nature of and emergence from CAS (McDaniel Jr & Driebe, 2001). For this study, relationships are between the patient, caregivers, and HCPs.

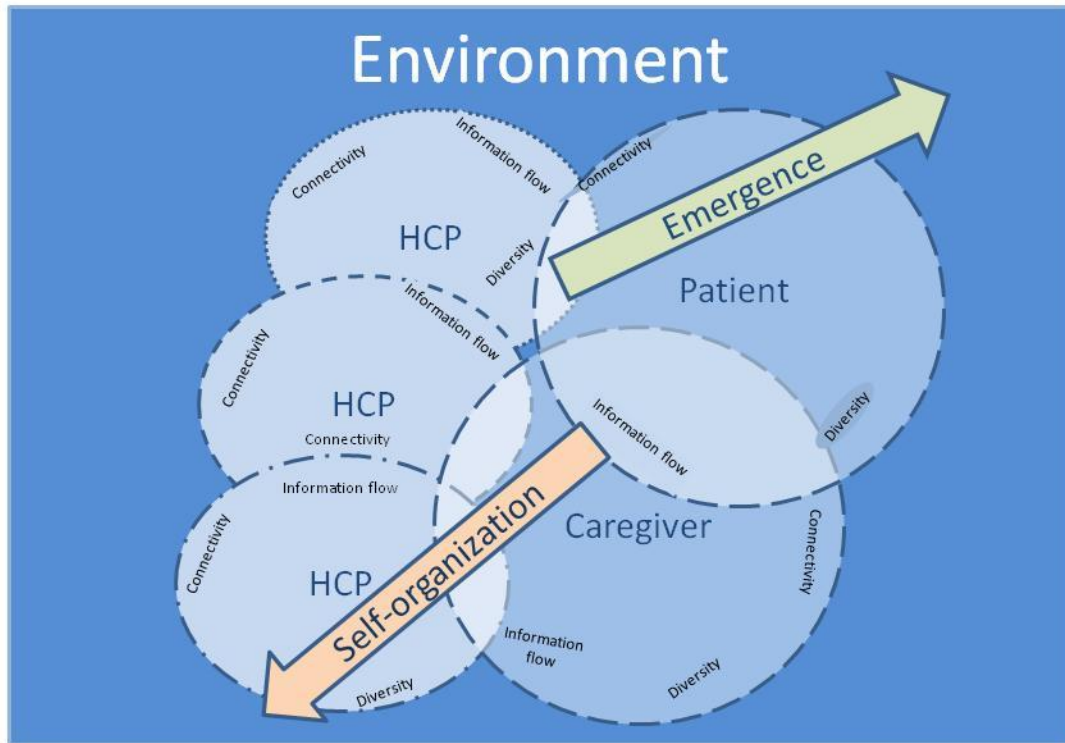
Self-organization – the process within, among, and between agents of changing behavior in response to information and in doing so organizing to create patterns that appear centrally planned, although they are not (Paley, 2007).

Skilled nursing care – Services provided in response to physicians' orders that require qualified technical or professional health personnel and must be provided by or under the supervision of skilled personnel to assure safety and to gain the needed medical effects (Center for Medicare and Medicaid Services, 2012)

Transitions – include the broader experience of transition, including the emotional and mental components.

Figure 1: Patient – specific Healthcare System

The patient-specific health care system is central to this model as it depicts the individual patient's facility-level context of care. Local environments (the blue background) affect the patient's care transition through local regulations and availability of services. HCPs and the systems they work in, indicated by color and shape, provide different products and services to the patient while following different professional guidelines as well as federal, state, and local regulations. The interactions among HCPs overlap or touch, but do not provide the same view of the patient or the same input into the patient's experience.

Figure 2: Complexity Science View of Transitions

As time flows: types, patterns and properties of current transitions for each agent varies, changing the dynamic for this transition

This model demonstrates key concepts within this study: patients, caregivers, and HCPs within their local environments acting together to support the patient during care transition from hospital to nursing home and 120 days beyond. These individual information agents are interdependent, but not without freedom to act.

Relationships vary, in part, based upon the connectivity, information flow, and cognitive diversity of the information agents. Through these relationship-based interactions, agents will self-organize and outcomes, such as QoL and unplanned utilization will emerge.

Chapter 2: Review of the Literature

Patient transitions from acute care hospitals (hospital) to nursing homes (NH) are common, affecting over 13 million patients over age 64 in the US during 2010 (HCUP Databases, 2010). Globally, the importance of hospital to NH transitions is also substantial. In Australia, hospital to NH transitions are the largest source of NH admissions (Karmel, Gibson, Lloyd, & Anderson, 2009). Likewise, in Finland, 6% of decedents were transitioned from general hospital to NH within the last 2 years of life during 2002 and 2003 (Aaltonen, Rissanen, Forma, Raitanen, & Jylha, 2012).

The volume of hospital to NH transitions indicates critical potential effects on outcomes and healthcare costs. However, research on this transition has been slow to develop compared to the large body of research on the hospital to home transition. Hospital to home transitions have been a focus for research since at least 1988 (Brooten et al., 1988) with multiple systematic reviews synthesizing findings. Reviews of hospital to home transitions described the transition (Borthwick, Newbronner, & Stuttard, 2009; Kelly, 2011; Nosbusch, Weiss, & Bobay, 2011; Zimmerman, 2012); identified and reviewed interventions (Aase, 2012; Chiu & Newcomer, 2007; Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011; Willey, 2012); and identified predictors of adverse outcomes (Brassard, 2011; Englander, 2011; Poletick, 2008).

In contrast, hospital to NH transition research began over 10 years later (Reed & Morgan, 1999) and publication of study results has only recently accelerated. Two systematic reviews including hospital to NH transitions have been published (Chhabra et al., 2012; LaMantia, Scheunemann, Viera, Busby-Whitehead, & Hanson, 2010). Neither focused solely on this transition, but rather included various transitions between acute and non-acute healthcare facilities. The first systematic review focused on interventions to improve accuracy and appropriateness of medication lists and/or advance directives. Only two of the five included studies involved the transition from hospital to NH (LaMantia et al., 2010).

The second was a systematic review of medication reconciliation intervention studies. Of the seven studies reviewed, only two included the transition from hospital to NH (Chhabra et al., 2012). To our knowledge, no systematic review has focused on the phenomenon of hospital to NH transition.

Recent acceleration of publications in light of the volume of hospital to NH transitions and their potential effect on patient and health system outcomes indicates an important and rapidly emerging field of research. Reviews of emerging bodies of research contribute to awareness of the scope of the field, areas of emphasis, challenges and limitations of the research, and areas ripe for future attention. Thus, we undertook an integrative review of studies of the hospital to NH transition. Our purpose was to describe key characteristics of this body of research and identify emerging themes and implications for future research and practice.

Background

The importance of hospital to NH transition volume in relation to clinical and financial outcomes is substantial. Hospital readmission, often considered a key quality measure for this transition in the US, has remained high and unchanged for 10 years. Roughly 19% of patients with five Medicare-flagged conditions who transitioned from hospital to NH were readmitted each year between 2000 and 2010 (Medpac, 2013). Pay for performance incentives demand improvement of this trend.

This stagnant readmission rate is consistently higher for patients transitioned from hospital to NH than for patients discharged from hospital to home. Seven studies addressing this discrepancy were published with increasing frequency between 2010 and 2014 (Allen et al., 2011; Copertino et al., 2014; Engelbert, Fernandes-Taylor, Gupta, Kent, & Matsumura, 2014; Hannan et al., 2011; Keller, Khorgami, Swendseid, Khan, & Delaney, 2014; Lavernia, Villa, & Iacobelli, 2013; Riggs, Roberts, Aronow, & Younan, 2010; Zhang, Schairer, & Feeley, 2014). While readmission rates varied substantially across clinical populations, in all cases readmission rates for patients transitioned from hospital to NH were higher

than for patients transitioned to other locations, such as home. Although intervention studies have demonstrated success in reducing readmissions following transition from hospital to home (Coleman et al., 2004; Coleman, Parry, Chalmers, & Min, 2006; Coleman, Fox, & HMO Workgroup on Care Management, 2004; Coleman, Min, Chomiak, & Kramer, 2004; Coleman et al., 2004; Coleman, Mahoney, & Parry, 2005; Jack et al., 2009; Naylor et al., 1999; Naylor et al., 2004), these interventions have not been investigated within hospital to NH transitions.

Researchers of the hospital to home transition have studied the transition as a unique phenomenon. In contrast, reviews of hospital to NH transition research, described within the Introduction, address this transition as one type among many. However, transition from hospital to NH is distinct from other transitions from the hospital (e.g., hospital to home) and other transitions to the NH (e.g., community to NH). This uniqueness is embedded in the patient clinical needs and associated resource requirements and the patient experience of the transition.

Prompted by an acute event or advancing chronic disease, hospitalization connotes an exacerbation in clinical needs. Following hospitalization, patient clinical needs often remain increased whether for the short or long term. For patients transitioning from hospital to NH, needs exceed the abilities of family caregivers and available social support systems within the community. Often, requirements are for continuous professional knowledge and skill to manage ongoing treatment and to monitor for exacerbations. Necessary equipment may also be unattainable within the home.

While clinical and associated resource needs distinguish the hospital to NH transition from other hospital transitions, it is often the patient and family emotional responses that separate this transition from community to NH transitions. Unfamiliar environments and routines within the NH are often disconcerting for patients and families. However, within the hospital to NH transition compressed timeframes, necessitated by hospital length of stay requirements, amplify these issues. With average

Medicare hospital lengths of stay between 5.4 and 6.6 days (Steiner, Andrews, Barrett, & Weiss, 2013) there is barely adequate time for the clinical decision making and administrative necessities of transition. Patients rarely have the opportunity to visit and personally choose their NH. Much less is the opportunity to grieve the loss of independence associated with the move.

Patient clinical needs and experience of the transition from hospital to NH indicates a unique phenomenon that deserves dedicated attention from researchers. In addition, substantial annual volume and stagnant outcomes indicate that new information is needed to improve care. A recent acceleration in research on early readmission within the NH population indicates increasing concern regarding transition quality and financial incentives to improve readmission rates. In this context, an integrative review provides a “more comprehensive understanding” of the phenomenon of transition from hospital to NH (Whittemore & Knafl, 2005). Therefore, the purpose of this review was to describe key characteristics of the body of research and to identify emerging themes and implications for research.

Methods

A literature search was performed in collaboration with two University librarians certified in systematic review methods following Institute of Medicine guidelines (Eden, Levit, Berg, & Morton, 2011). PubMed, CINAHL, and Scopus searches were conducted with the intent of gathering all studies focused on the phenomenon of transition from hospital to NH. In addition, a hand search for relevant articles was conducted using the reference lists of the reviews mentioned above and the articles included within this review. Three additional articles were included. (See Box 2.1).

I completed the initial review of abstracts, removing duplicates and articles without transition from hospital to NH as a central phenomenon. Two members of the Dissertation Committee read and

discussed each of the remaining articles, using the inclusion and exclusion criteria described below to determine the final set of articles.

Movement from hospital to NH was the index transition. Transition was defined as a process rather than a single event. Therefore, studies were excluded that addressed the decision to transition to NH from hospital as a point in time event, but included studies of the planning and coordination. A NH was determined to be a 24-hour nursing provider including both long term and short term care for rehabilitation and skilled nursing. This definition is consistent with that of the American Medical Director's Association (American Medical Directors Association, 2010).

Inclusion criteria were: research articles with a prominent focus on the index transition with findings related to the hospital to NH transition reported discretely from any other transition (e.g., NH to ER). Exclusion criteria were: non-data based publications; and publication in a language other than English. No limits were placed on publication date.

An initial review of the research literature revealed considerable heterogeneity in methods and findings. Qualitative, quantitative, and mixed methods were included. Integrative reviews provide an ideal approach for synthesizing methodologically heterogeneous bodies of literature (Whittemore & Knafl, 2005). Thus, this approach was selected, using the methods described in the literature (Nosbusch, et al., 2011; Whittemore & Knafl, 2005). Research questions, operational definitions, methods, and data sources were first compared through the use of matrices. To begin to qualitatively synthesize study findings a narrative summary of each study was developed and key findings were compiled in table format. Then, a thematic analysis was conducted through categorization, constant comparison, and identification of cross-cutting themes in the study findings.

Results

Characteristics.

Of 927 articles retrieved, 25 met inclusion criteria (Figure 2.1). Fifteen were conducted in the United States; four in Australia; two each in the United Kingdom and Canada; and one each in Sweden and Finland. First authors included physicians, nurses, pharmacists, academics and researchers, data analysts, and PhD students. The earliest study was published in 1999. Fifteen of the 25 (60%) were published between 2011 and 2014.

Methods included quantitative, qualitative and mixed methods approaches. Eighteen of the studies were descriptive. Qualitative studies were predominantly semi-structured individual or focus group interviews of professionals, patients, and family members. Surveys, both mailed and online, were used in four studies. Medical record review was used in five studies. One used Delphi methods. Six intervention studies included a pilot and an action research study. Intervention study designs used controls ranging from pre / post intervention measures using convenience samples to randomized controlled trials. (See Table 2.1).

These intervention studies addressed continuity of care in medications and advance directives (Boockvar, Carlson LaCorte, Giambanco, Fridman, & Siu, 2006; Crotty, Rowett, Spurling, Giles, & Phillips, 2004; Ward et al., 2008; Zafirau, Snyder, Hazelett, Bansal, & McMahon, 2012). While most of the studies demonstrated positive effects on measured outcomes, only the single study implemented by research staff was fully implemented (Boockvar et al., 2006). Studies dependent on NH staff implementation were implemented inconsistently across research sites and study arms (Crotty et al., 2004; Zafirau et al., 2012). One study achieved no implementation at the NH (Ward et al., 2008).

Data sources were variable, but multiple data sources were typical. One study used expert opinion as the major data source. Two studies were completed using only hospital data and five using

only NH data. Two studies used administrative data sets. Fifteen addressed the transition using multiple data sources, including patient, caregiver, and healthcare provider interview, hospital and NH medical record data and administrative data.

The body of research was methodologically heterogeneous in critical areas: terminology, operational definitions, research problem and purpose. Nine different terms were used to describe the facilities defined within this paper as 'nursing homes.' Practical and policy differences related to facilities described using different terms, such as required staffing patterns or extent of hospital lengths of stay, were mentioned in only a small minority of studies. Operational definitions of transitions also varied. Each operational definition was reasonable given the individual study research purpose. (See Table 1). A single study identified the research problem as a lack of research on the transition from hospital to NH (Reed & Morgan, 1999). All the others focused more narrowly on one aspect of transition such as a single clinical process or one perspective. As such, purposes, with few exceptions, addressed isolated processes or points of view. (See Table 1).

Frameworks were described in four studies. (Boockvar & Burack, 2007; King et al., 2013; Reid et al., 2013; Shah, Burack, & Boockvar, 2010). The earliest two publications used Donabedian's model of quality within healthcare (Donabedian, 2005) in combination with a model of care transfer (Anderson & Helms, 1998) to develop a "model of factors" proposed to affect interorganizational patient care transfers. They developed a survey based on this model of factors to identify organizational factors and hospital and NH relationships associated with more efficient care transition processes (Boockvar & Burack, 2007; Shah et al., 2010). The third study was a conceptual model developed as a result of grounded theory dimensional analysis of skilled nursing facility (SNF) nurses' transitional care. Poor quality of written hospital discharge information determined the transition process and consequences on care delivery and individual outcomes within the model (King et al., 2013). The fourth study (Reid et al., 2013) used process mapping to inform a complicated conceptual framework of transitions between

NHs and emergency departments. Across the processes, transition success was evaluated using the IOM Quality Framework in relation to individual, care-unit, and facility level factors (Cummings et al., 2012).

Although the guiding frameworks were developed using differing methods, the first three linked hospital communication to NH outcomes. Each used unique concepts and suggested distinct relationships between the concepts. However, the result in each case was the connection of completeness of hospital communication with NH outcomes. The final framework supported protocol development for a substantial study of transitions between emergency departments and NHs, a subset of the hospital to NH transitions.

Themes

Through the integrative analysis of these heterogeneous studies, five themes emerged. They are: Patterns of Healthcare Utilization, Individual Perspectives, Getting What the NH Needs to Provide Care, Continuity of Care, and Strategies to Improve.

Patterns of Healthcare Utilization. The “Patterns” theme relates to studies that evaluated configurations of population-level healthcare utilization. These studies of regional (Aaltonen et al., 2012; Karmel et al., 2009; Ma, Coleman, Fish, Lin, & Kramer, 2004) and diagnostic (Popejoy, Dorman Marek, K. & Scott-Cawiezell, 2013) aggregates represent significant advances in knowledge of utilization patterns and predictors. Multiple data sources and/or novel data linking techniques were used to illuminate patterns unseen previously. These data sources included more than one administrative database (Aaltonen et al., 2012; Karmel et al., 2009) or combinations of medical record, interview (Popejoy et al., 2013) and administrative data (Ma et al., 2004).

These studies attempted to identify pattern characteristics that are open to policy or practice changes to improve outcomes. Patterns were identified in terms of location prior to the index hospitalization (Popejoy et al., 2013), baseline functional ability (Popejoy et al., 2013), payment

mechanism (Ma et al., 2004), and geopolitical boundaries (Aaltonen et al., 2012; Karmel et al., 2009). While findings may not be broadly generalizable, they do call to question conventional wisdom regarding patients who transition from hospital to NH, such as the importance of managed care to decrease utilization of health services.

Although the studies addressed multiple populations and discrete questions, limiting direct synthesis, integration of findings across the process was possible. This integration provided insight into healthcare utilization patterns. Among hip fracture patients in a multiple case study, most patients were admitted to the hospital from home. Those who transitioned to SNF following hospitalization, rather than to an inpatient rehabilitation facility, were less likely to return to baseline functionality. However, pre-hospital baseline functionality of patients transitioned to SNF was lower than that of patients discharged to inpatient rehabilitation, as well (Popejoy et al., 2013). In another study, patients discharged from hospital to SNF or inpatient rehabilitation experienced the same pattern of transitions regardless of payment mechanism. However, those who died during the study had more transitions than those who survived until study completion (Ma et al., 2004). Finally, geopolitical boundaries, such as hospital districts or state of residence, were found to be important in describing variation in utilization of healthcare services broadly (Aaltonen et al., 2012) and specifically to NHs following hospitalization (Karmel et al., 2009) in some instances.

Individual Perspectives. Individual perspectives describe the way transition participants experienced and viewed meanings of the transition from hospital to NH. Individual perspectives studied included patient, caregiver, and multiple healthcare providers. While perspectives differed, none of the participants were satisfied with their transition experiences.

Studies of individual perspectives make clear that role and location held implications for experience in transition. While patients described the move to a NH as a “profound change” (Reed &

Morgan, 1999, p. 823), patients in the two relevant studies considered themselves to lack control (Digby, Moss, & Bloomer, 2012; Reed & Morgan, 1999). Perhaps contributing, patients tended to be outside of decision making regarding the transition, either by their choice or that of others (Digby et al., 2012; Reed & Morgan, 1999). While family support was comforting, patients also experienced anxiety about what would happen next (Digby et al., 2012). Patients perceived a variety of threats to their personhood, despite differences in sample characteristics, research settings, and the fact that 12 years separated the two publications (Digby et al., 2012; Reed & Morgan, 1999).

Family caregiver experiences were least studied, with only one study reporting their perspectives. Within the hospital, family members were found to be most likely to question the need for placement that healthcare providers deemed necessary and patients tended to accept stoically. The hospital-dictated move did not provide adequate time or support for family members to evaluate placement options (Reed & Morgan, 1999).

NH care provider engagement of family members differed across two studies. In a prospective study of hip fracture patients, family members were described as “experts in knowing what is normal” who often identified patient problems and needed services before staff recognized the issues (Popejoy et al., 2013, p. 50). However, a qualitative study of NH nurses described patients and family members as unable to provide needed information at transition due to lack of information or capability. The nurses within this study also described concern that asking questions left a poor impression of the NH without resolving information gaps at transition due to need for physician orders (King et al., 2013).

Staff nurses, whether from hospital or NH, were not satisfied with their experience of patient transition. Studies of NH nurse experience consistently reported inadequate information received about patients and concern that patients were often not clinically ready for the NH level of care (King et al., 2013; Kirsebom, Wadensten, & Hedstrom, 2012; Popejoy, Galambos, & Vogelsmeier, 2014). Significant

time and energy were noted in the filling of information gaps (King et al., 2013; Popejoy et al., 2014). Fragmentation of NH roles in the transition of patients (Lester, Stefanacci, & Chen, 2009) may have contributed to these concerns. However, concern was voiced more frequently in terms of frustration with hospital staff and/or practices (Boockvar & Burack, 2007; King et al., 2013; Kirsebom et al., 2012; Popejoy et al., 2014). In some cases, the frustration was associated with negative perceptions about hospital staff (Boockvar & Burack, 2007; King et al., 2013; Kirsebom et al., 2012).

Hospital staff nurses also voiced concern with their practices. They reported that it was difficult to know when to send the patient to a NH, acknowledging that, with chronically ill patients, the end of hospital treatment was not always clear. Attempting to stop discharges that appeared too early or inadequately prepared often met with resistance from within the hospital. In addition, they felt rushed to attempt to meet discharge requirements within necessary timeframes for NH admission (Kirsebom et al., 2012). In some cases, they voiced suspicion regarding the quality of care in NHs (Reed & Morgan, 1999) and described NH staff as less qualified than hospital staff. Hospital nurses believed NHs to be rigid with little room for patient preference (Reed & Stanley, 2003).

Fragmentation of hospital roles may have contributed to these experiences. Isolated and narrow hospital-based roles were identified in the discharge process in the context of an “ad hoc” nursing approach to transition to NH. Physicians determined the timing and level of care within the move. Social workers reported little time to discuss options with patients and feeling that counseling was lost to their administrative role. Hospital staff nurses admitted to knowing little about care homes and feeling that they had little support to give. In this fragmentation, counseling and support functions were lost (Reed & Morgan, 1999).

Interestingly, none of the participants were pleased with their personal experiences or meanings within the transition from hospital to NH. Each participant appeared to understand limitations and some

needs within the other roles, but felt frustration and/or isolation within their own. Self-reflection within individual practices appeared limited to a single action research study. Within this study, hospital nurses became more aware of NH practice and what the move meant to the individual patient. Following implementation of a tool to support person-centered care, some nurses were more satisfied with transitions (Reed & Stanley, 2003).

Getting What the NH Needs to Provide Care. NHs struggled to get all the information that they needed in the necessary format and with adequate lead time to provide care to patients on admission. The body of literature refers frequently and critically to hospital communication with the NH throughout the process of transition. However, there was a distinct link between hospital communication inadequacies and unique NH regulatory requirements and resource availability.

Communication processes were described as largely paper-based and at least somewhat unreliable (King et al., 2013; Lester et al., 2009). Hospitals inconsistently sent needed information (King et al., 2013; Kirsebom et al., 2012) and often sent too much information, making determining relative importance and finding needed information challenging for NH staff (King et al., 2013; Popejoy et al., 2014). “[M]uch of the information nurses needed” was “routinely missing or incomplete, conflicting, or discovered to be inaccurate” (King et al., 2013, p. 3). Nearly 1/3 of NH respondents did not receive “all the information needed to care for” residents transitioning from the hospital as consistently as “often” (Boockvar & Burack, 2007, p. 1081). Post-hospital treatment plans (Lester et al., 2009), ER and inpatient discharge summaries (Lester et al., 2009; Reid et al., 2013) and treatment results are examples of frequently missing documentation (Reid et al., 2013).

Correcting miscommunications or filling gaps in communication was noted to be a consistent and frustrating problem for NH nurses that required significant time and effort (King et al., 2013; Popejoy et al., 2014). In working to fill gaps or correct conflicting and inaccurate communication at

transition, NH staff used techniques such as seeking, reviewing, gathering, and reconciling to develop and implement an appropriate plan of care (King et al., 2013). These efforts were necessary because hospital staff reporting on or responding to questions about the patient did not consistently know the patients. Hospital staff who did know the patients were frequently not available to speak with NH staff (King et al., 2013; Popejoy et al., 2014). This clarification process was reported to require more than 30 minutes and up to 3 hours for each patient (Popejoy et al., 2014).

These communication delays and clarification processes fed into logistics issues unique to NHs. Limited resources including professional staff, medications, supplies, and equipment complicated NH efforts to meet new patient needs. As such, afternoon and weekend discharges, common for hospitals, presented problems for NHs (King et al., 2013; Kirsebom et al., 2012; Popejoy et al., 2014). Decreased staffing with lower professional availability in NHs made responding to professional needs difficult after hours (Kirsebom et al., 2012). Absence of 24-hour pharmacy and limited access to specialty equipment hampered the ability to obtain medications, equipment and supplies after hours (Kirsebom et al., 2012). NH-specific regulatory and practice requirements, such as the need for signed paper copies of opioid prescriptions, were noted as a frequent issue with few NH options to resolve without delays in patient care (King et al., 2013; Kirsebom et al., 2012; Popejoy et al., 2014).

Transfer of medication records to NHs was noted as a specific problem to the provision of care at transition in the context of limited pharmacy resources (Boockvar & Burack, 2007; Lester et al., 2009; Popejoy et al., 2014; Reid et al., 2013). Medication administration and last given medication records were noted to be commonly missing (Lester et al., 2009). As might be suspected, delay and omission of medications at transition were concerning. When medications were supplied by the hospital, 18.3% of patients missed or were significantly delayed in receiving at least one dose of medication (Elliott et al., 2012). Where medications were not supplied by the hospital at transition, only patients who did not have medications due in the evening following transitions received all ordered medications. On average,

the first medication dose was received 12.5 hours after arrival in the NH (Ward et al., 2008). These delays were related to delivery of required documentation too late in the day to allow pharmacy delivery before the end of business.

Formal organizational affiliations were discussed as a potential method for improving these issues. However, formal relationships were not found to be a panacea. Hospital and NH affiliations were associated with better document transfer, but not with better communication between hospital and NH nurses or physicians (Lester et al., 2009). However, NHs contracting hospital laboratory or pharmacy services or having staff cross-site visits were associated with a reduction in the perception of some barriers to communication at transition (Shah et al., 2010). Smaller hospital size and higher frequency of hospital geriatric care within the primary hospital provider were associated with NHs receiving all needed patient information more often (Boockvar & Burack, 2007; Shah et al., 2010).

Continuity of Care. Continuity of the established plan of care upon transition was a concern across multiple studies. Continuity of care was discussed as important to decrease risk for adverse events, to improve patient satisfaction and to align with patient wishes, and for adherence to standards. Unlike “Getting What the NH Needs to Provide Care,” continuity of care depends upon communication of the rationale for the existing plan of care from the discharging facility and the acceptance of that plan of care by the admitting facility.

Three studies evaluated information adequacy from the discharging facility perspective. Internal quality improvement studies used only internal hospital documentation to determine hospital adherence to standards, both internal and regulatory (Burton et al., 2012; Kind & Smith, 2008). While study findings gave evidence of individual hospital performance, they provided little evidence of the received value to the NH. One intervention study aimed to improve communication of advance directives across the continuum of care. In conjunction with improved communication of advance

directives, admissions to palliative care increased within the study. Study authors considered this to be improved alignment with patient wishes (Zafirau et al., 2012).

In three descriptive studies, medication reconciliation was reported to identify unintended medication discrepancies (Sinvani et al., 2013) and to reduce adverse drug events due to medication discrepancies at transition (Boockvar et al., 2004; Boockvar et al., 2006; Sinvani et al., 2013). Although each of these studies described medication discrepancies from hospital to NH, none link this pattern to the unique nature of the transition. As an example, studies noted an increase in number of prescribed medications from hospital to NH as a discrepancy. No description of the new medications or clinical / practice differences associated with the changes were offered. However, an increase in the number of 'as needed' medications in the NH, given the lack of available prescribers within the facility, would be expected. As importantly, each study, including a Delphi study intended to develop quality measures for the transition (Bell, Brener, Comrie, Anderson, & Bronskill, 2012), used distinct operational definitions of discrepancy, making synthesis of knowledge from the studies problematic.

Continuity of care beyond medications was also addressed. Researchers described follow through with the recommended plan of care at transition. Nearly 40% of patients transitioned from NH to hospital and back were found to have been provided hospital care that was inconsistent with "health and functioning goals" from the original NH stay. No comment was made as to whether the NH accepted the revised hospital goals or returned to the original upon patient return to the NH (Boockvar & Burack, 2007). Likewise, follow through on hospital recommendations to NH showed evidence of discontinuity. Of the recommendations made to NHs by hospitals, 24% had no documentation of follow-up within 6 months of hospital discharge. Reason for declining to follow-up was documented in only 35% of cases. As the number of hospital provider recommendations increased, the number of recommendations followed decreased (Caruso, Thwin, & Brandeis, 2014).

Strategies to improve. Study findings directly pointed to options or “solutions” for improving transition from hospital to NH. Operational and relationship suggestions dominated. Operational strategy recommendations often related to changes within a single process or intervention. However, NH staff also suggested strategies around timing of transitions and improved communication from hospital to NH (King et al., 2013; Kirsebom et al., 2012). Hospital staff recommended increasing NH resources to better support patient needs at transition (Kirsebom et al., 2012). These strategies, suggested from isolated perspectives, revealed lack of awareness of barriers to implementation in other levels of care. However, studies encompassing both the hospital and the NH perspectives suggested discussion between individual hospitals and NHs to deal with problematic situations and issues (Popejoy et al., 2014; Reed & Stanley, 2003). For example, instituting a communication plan for both nursing staff and physicians between facilities was recommended (Popejoy et al., 2014).

Relationship strategies suggest options for improving transition through facility and operations-level relationships. Findings related to these relationships were inconsistent, with studies showing improvements in some measures of communication, but not all (Boockvar & Burack, 2007; Lester et al., 2009). In a single study, the improvements in communication gained from hospital and lab service contracts and cross-site staff visits were described in terms of “perception of the barrier” rather than direct improvement in the process. Nursing staff suggestions encouraged increased communication, interaction and mutual problem solving such as action research (Reed & Stanley, 2003), job rotation, scheduled meetings and increased opportunities to work together. In this context, “[b]oth groups believed that nurses from the other care setting would benefit from learning about the setting they themselves worked in” (Kirsebom et al., 2012, p.8). Action research across facilities showed improvement in hospital and NH nurses’ awareness of patient needs at transition (Reed & Stanley, 2003).

Discussion

The Blind Men and the Elephant
John Godfrey Saxe (1816-1887)

It was six men of Indostan
To learning much inclined,
Who went to see the Elephant
(Though all of them were blind),
That each by observation
Might satisfy his mind.

The *First* approached the Elephant,
And happening to fall
Against his broad and sturdy side,
At once began to bawl:
"God bless me! but the Elephant
Is very like a WALL!"

The *Second*, feeling of the tusk,
Cried, "Ho, what have we here,
So very round and smooth and sharp?
To me 'tis mighty clear
This wonder of an Elephant
Is very like a SPEAR!"

The *Third* approached the animal,
And happening to take
The squirming trunk within his hands,
Thus boldly up and spake:
"I see," quoth he, "the Elephant
Is very like a SNAKE!"

The *Fourth* reached out an eager hand,
And felt about the knee
"What most this wondrous beast is like
Is mighty plain," quoth he:
"'Tis clear enough the Elephant
Is very like a TREE!"

The *Fifth*, who chanced to touch the ear,
Said: "E'en the blindest man
Can tell what this resembles most;
Deny the fact who can,
This marvel of an Elephant
Is very like a FAN!"

The *Sixth* no sooner had begun
About the beast to grope,
Than seizing on the swinging tail

That fell within his scope,
"I see," quoth he, "the Elephant
Is very like a ROPE!"

And so these men of Indostan
Disputed loud and long,
Each in his own opinion
Exceeding stiff and strong,
Though each was partly in the right,
And all were in the wrong!

http://www.constitution.org/col/blind_men.htm (12/5/14)

Hospital to NH transition is a complex process. The 25 studies in this review collectively described a complex process. The narrow research questions each addressed a part of the phenomenon, much as each blind man in Saxe's poem above (Saxe, n.d.) described a part of the elephant. Descriptions of the elephant's trunk as a snake and the tail as a rope are akin to descriptions of hospital staff as lacking effort and NH staff who are less knowledgeable than hospital staff. From a single perspective and without context, these descriptions appear true. However, with broader context, a more accurate picture may emerge. Without context, readers cannot develop a complete picture of the elephant.

In the absence of a complete picture, we are able to define transition from hospital to NH as complex based on the descriptions within this literature. There are multiple agents (participants) actively engaged, learning and changing based on knowledge gained within the experience. The agents are individuals with different expectations, needs, and experiences of transition from hospital to NH because they come to the transition with different roles (e.g., patient, family member, multiple professionals, etc.) and different contexts (e.g., professional practice acts, regulatory requirements, cultural norms, etc.). None of the agents have full understanding of the transition. For this reason, the agents are interdependent with other agents within the transition. Interactions among these interdependent agents are non-linear: small changes lead to large differences in outcome. Likewise,

large efforts can lead to small changes. These disproportionate outcomes emerge from the dynamic interaction among the agents.

Themes reflect issues of this complexity. The themes that emerged from this literature reflect this complexity. Although no participant group was happy with their experience, each individual perspective reflected a unique experience. For example, patients felt loss and behaved stoically; family members doubted the need for NH placement and were overwhelmed by the speed of transition. “Getting What the NH Needs to Provide Care” and “Continuity of Care” reflected differing values and a lack of understanding of information needs and treatment goals between facilities. These differences were at least in part related to different contexts such as regulatory requirements and practice norms within the facilities (e.g., pressure to discharge within the hospital; time requirements to obtain needed equipment in the NH). Reliance on paper-based communication mechanisms limited interaction and perpetuated the effects of these differences. In addition, difficulty in identifying patterns across the transition process prevented learning necessary for the agents to effectively modify behavior. Compressed timeframes and fragmented responsibilities within the hospital and the NH further discouraged dynamic interaction necessary for information exchange.

Characteristics of the body of research are also related to complexity. The heterogeneity characteristic of this body of research was the result of multiple partial views of the complex phenomenon. These studies represented the agents’ experiences within shared portions of transition. Likewise, geopolitical boundaries were assumed from the study location with only a few addressing the importance of those factors on findings. The research questions, terms, and operational definitions reflected these partial views. As a result, individual studies were coherent and insightful without connecting to a larger, more complex process.

Knowledge development requires a consistent lens. Like the blind men within Saxe's (n.d.) poem, this field needs a cohesive and holistic view of transition to support placing findings from individual studies in the context of the whole transition. A consistent and holistic theoretical framework would provide the needed support. Theoretical frameworks, intended to both guide the development of a study and link findings back to the larger body of knowledge are beginning to emerge. Three of the four identified frameworks, however, are mid-range or narrower theories which described only a part of transition. To date frameworks have addressed a single perspective (e.g., NH staff). These narrow theories did not allow for individual study findings to be linked back to further build knowledge of the larger transition process. The fourth is a complicated model of transitions between NHs and emergency departments. Its relationship to hospital to NH transitions has yet to be tested.

This lack of a cohesive and consistent theoretical framework contributed to the sense of heterogeneity characteristic of this body of research. The 25 studies spanned 15 years, 6 countries and at least 5 professions. Studies of multiple individual perspectives within several sub-processes, while individually important and thoughtfully completed, floated rather than connecting clearly to the whole. Without a frame to guide connection of the individual findings, individual interpretations and focused discussions hampered knowledge building within the body of research.

We propose viewing the transition process as the interaction of multiple complex adaptive systems (CAS). The IOM declared healthcare systems to be CAS in a landmark report first published in 2001 (Committee on Quality of Health Care in America, 2001). This declaration sets aside old assumptions about how health systems work and proposes new ways of considering both research and practice. Within this body of research, such a view offers great potential to inform future research.

CAS as a lens for transition from hospital to NH. A complete description of CAS is beyond the scope of this work. However, key to understanding the value are the central qualities of CAS. Each CAS is

made of learning agents who interact with and are dependent upon their environment. These agents change their behavior based on new knowledge in the context of their environment (self-organization). While these agents interact with and are interdependent with one another, they are not aware of another's complete context. Therefore, it is the relationship – the dynamic interaction -- between these agents that allows for the sharing of information necessary to achieve improved results through self-organization. Critically important, while the agents are interdependent, their interdependencies are non-linear. Therefore, small efforts can lead to large or even unanticipated changes (McDaniel & Driebe, 2001).

Connecting several static descriptions from individual perspectives may provide greater insight to the implications of the dynamic described above. NH staff, who needed additional information at patient admission from hospitals, sent out lists of information requirements for hospitals at discharge (King et al., 2013). Hospital staff reported a lack of understanding of NHs, fragmented processes within the hospital, and limited time (King et al., 2013; Reed & Morgan, 1999). Hospital staff nurses were described as sending “reams” of paper to the NH (King et al., 2013; Popejoy et al., 2014). From the hospital perspective, this should have ensured that the NH had everything that they needed. From the NH perspective, it overwhelmed and increased the potential that conflicting information was received. In this situation, lack of contextual understanding and dynamic interaction limits the ability of both agents to meet the needs of the other. It does not, however, hamper behavior change based upon learned information.

“Real power lies in the way the parts come together and are interconnected to fulfill some real purpose” (Plsek, 2001). Interconnections do not imply electronic health record solutions, but rather relationships. In the example above, interconnections (relationships) were limited to requests. Limited context and understanding to frame the request actually hampered building the relationship and likely further damaged quality. Interestingly, it was staff within these studies who called for additional

interaction and increased knowledge to feed improvement (Kirsebom et al., 2012; Popejoy et al., 2014). Likewise, while formal organizational relationships failed to improve communication, sharing resources such as laboratory and pharmacy (Shah et al., 2010) improved perception of communication. Looking through the lens of CAS, this increased interaction improves opportunity for learning and building relationships. Dynamic interactions thrive on both formal and informal opportunities to interact and exchange information.

Implications for research and practice. Viewing transition from hospital to NH as the dynamic interaction of multiple CASs would substantially change future research, beginning with the research questions. Within this body of literature, most researchers asked questions that parsed the process into smaller sub-processes viewed as events (e.g, discharge summary documentation, medication reconciliation, etc.) or focused singularly on one facility or participant. While these research questions made control and data management more achievable, they also placed dynamic interactions out of focus. From a CAS viewpoint, it is these dynamic interactions and the associated interdependencies that offer great potential for identifying opportunities for improvement (Anderson, Crabtree, Steele, & McDaniel, 2005).

The research questions within this body of research focused narrowly. In doing so, researchers effectively minimized the study of context. Within research completed using a CAS frame, context is recognized as key to understanding the dynamic interaction as well as to determining potential for implementation within practice. Therefore, under a CAS framework, research focused on small numbers with provision of substantial contextual information is typical (Anderson et al., 2005). Purposeful sampling within these smaller studies provides evidence of the implications of differences in context and dynamics (McDaniel & Driebe, 2001). Case study methodology has been suggested as a strong method for achieving these results (Anderson et al., 2005).

Research completed within a CAS framework also recognizes non-linear processes as typical. Because small changes can lead to large differences and because agents within the study continue to learn throughout the study, flexibility is critically important. Research design that is flexible to ongoing findings and changes within the study allows the researcher to capitalize on serendipity. Within flexible designs, findings different than anticipated can be allowed to drive changes in the study design. For example, within intervention studies where implementation is lower than anticipated, researchers could stop the study. Within the pause, the researchers could identify obstacles to implementation and make modifications to the intervention based upon findings. These approaches balance sensitivity to local conditions with study rigor (Leykum, Pugh, Lanham, Harmon, & McDaniel, 2009).

With the recognition that context is important comes the expectation that a single “best” practice is unlikely. Rather, “best practices” would be anticipated to be replicable only with modifications to accommodate differences in context. In proposing options for change within processes such as transition, it is likely that no single practice will work within differing facilities. Therefore, reporting of interventions with the context related to results allows more effective translation of practice. Methods such as action research, social network methods and simulation could provide insight to support selection of interventions within a specific situation.

Finally, given interdependencies, studies completed under a CAS framework would be drawn to include multiple perspectives. These multiple perspectives can be accommodated through qualitative methods engaging multiple participants. Quantitative and mixed methods approaches can also accommodate multiple perspectives through the use of variables and outcomes important to each perspective or through the use of research boundaries that allow connection beyond a single perspective (Anderson et al., 2005; McDaniel & Driebe, 2001).

Summary

The transition from hospital to NH is common and critically important for the patient and the healthcare system. However, measures of quality indicate stagnation. Increasing numbers of studies completed globally and across multiple disciplines indicate an area of significant interest. Within this review were 25 heterogeneous studies. Four of the studies described theoretical foundations. Identified themes included Patterns, Individual Perspectives, Getting What the NH Needs to Provide Care, Continuity of Care, and Strategies to Improve.

Transition from hospital to NH is a complex process. Heterogeneity seen within this body of research reflects partial views within research lacking the guidance of a broad and cohesive guiding framework. Emergent themes reflect individual and disconnected perspectives.

A complex adaptive systems framework is suggested for future research. Such a framework will emphasize the importance of dynamic relationships and context necessary to a view of the whole in achieving improved outcomes.

Figure 2.1: Literature Search Strategy**CINAHL Search Strategy:**

(transitional OR transition OR transitioning OR move OR moved OR moving) OR (MH "Transitional Programs")

AND

((MH "Hospitals+") OR (MH "Inpatients") OR (MH "Hospitalization+") OR (MH "Aged, Hospitalized") OR hospital*)

AND

((MH "NHs+") OR "snf" OR care w2 settings OR care w2 setting OR destination OR destinations OR care w2 facilities OR care w2 facility OR subacute w2 care OR (MH "Rehabilitation Centers+") OR (MH "Health Services for the Aged"))

Limits: All languages

All years

Age groups: adult

SCOPUS search strategy:

TITLE (transitional OR transition OR transitioning) AND TITLE (hospital* OR inpatient*) AND ("NH" OR "NHs" OR destination* OR "subacute care" OR "skilled nursing facility" OR "skilled nursing facilities" OR "care setting" OR "care settings" OR snf)

Limits All languages, all years

Note—Removed text word of move or moved or moving as produced too many irrelevant citations and added "snf" as a key word

PubMed/Medline strategy:

(transitional OR transition OR transitions OR transitioning OR transitioned)

AND

(hospital OR hospitals OR hospitalized OR hospitalization OR inpatient OR inpatients) OR ("Hospitals"[Mesh]) OR "Hospitalization"[Mesh]) OR "Inpatients"[Mesh])

AND

("NHs"[Mesh] OR "Rehabilitation Centers"[Mesh] OR "Homes for the Aged"[Mesh] OR "Health Services for the Aged"[Mesh]) OR

("NH" OR "NHs" OR destination OR destinations OR "rehabilitation center" OR "rehabilitation centers" OR "snf" OR "skilled nursing facility" OR "skilled nursing facilities" OR "care facility" OR "care facilities" OR "care setting" OR "care settings" OR "subacute care" OR "sub-acute care" OR "sub acute care" OR "skilled nursing services" OR "skilled nursing service" OR "nursing facility" OR "nursing facilities") [all]

Figure 2.2: Flow Diagram of Literature Search

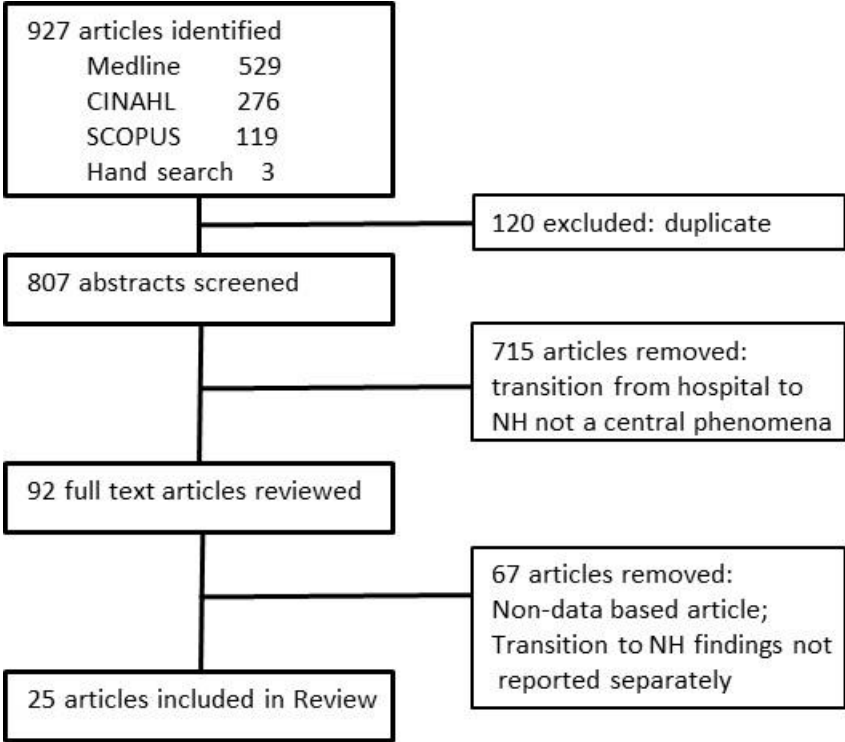


Table 2.1: Publications within the Review in Chronological Order

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures /Data Collection	Findings
(Reed & Morgan, 1999)	<p>To investigate experiences of older people and to identify possible forms of support that might be needed</p> <p>Seek comments from staff regarding how they saw the process of discharge from hospital to care home and what support they feel was needed or available</p>	Qualitative multiple perspectives, as a component of action research	<p>N=20 older patients, n=17 patient caregivers, n=33 MD, social worker, ad RNs from a hospital in <u>England</u> and care homes within the independent sector in the same region</p> <p>Purposeful sampling</p>	<p>Patients and caregivers were visited within 4 weeks of hospital discharge Loosely structured interviews</p> <p>Healthcare provider (n=23) individual interview, (n=1) semi-structured questionnaire (n=6)</p>	<p>Patients experienced the move as a profound change; were not typically offered the opportunity to discuss the move with nurses, and were not included in placement decisions. Patients tended to be stoic. Family members described moves as rushed and were about the need for transition to a care home.</p> <p>Professional roles were unilateral and non-interactive: Hospital nurses and social workers reported feeling that they did not have much support to offer to patients.</p>
Reed & Stanley (2003)	To report on a study which developed a tool that aimed to promote person-centered integrated care for older people moving from the statutory sector hospital service to the independent sector care home service	Action research Hospital and NH staff themes	<p>Hospital (n=37); and care home staff (n=19) in the <u>UK</u> supported development of the tool</p> <p>Hospital (11), care home (19) staff, and patients (19) evaluated the tool</p>	Action research 3 stage study process: tool development, use, and evaluation with 19 elders.	<p>Nurses found use of the tool to improve communication and understanding regarding individual patient needs and implications of transition. Use of the tool was inconsistent.</p>

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures / Data Collection	Findings
Boockvar, et al (2004)	To measure the frequency of changes and discontinuations in medication use that occur at the time of transfer between hospital and NH in both direction	Medical record review Hospital admission	N=87 NH residents admitted to 2 US hospitals for ≥ 24 hrs	Linear / logistic regression. Medical record review. Medication orders from sequential sources Linear / logistic regression.	Mean number of medications changed from NH to hospital was 3.1 and from hospital to NH was 1.4. Adverse drug events attributed to medication changes during 20% of the 71 bidirectional transfers with overall risk of ADE was 4.4%. Most of the medication changes occurred in the hospital, but most ADEs occurred in the NH after patient return.
Crotty, et al (2004)	To investigate whether the quality of 1st-time transfer of older patients from a hospital to long-term residential care facility would be improved by having a pharmacist coordinate the transition...	Randomized single-blind controlled trial Intervention vs. control	N=44 older patients making a 1 st time transition from hospital to LTC in each of the intervention and control groups in <u>South Australia</u>	Intent-to-treat analysis, independent t-tests and Mann-Whitney U tests. Intervention = faxed medication transfer summary; coordinated medicine review and case conference. Charlson Comorbidity index; Medication Appropriateness Index; number pre-admission medications; medications changes during admission; number medications baseline and follow up.	The majority of patients changed physicians in the context of the transition to the NH. At 8-week follow up, there was no change in MAI in the intervention group, but it had worsened from baseline in the control group. Patients living at 8 weeks in the intervention group showed a significant protective effect against worsening pain and hospital usage. When data for patients who had died were included, the intervention had no effect on hospital usage.
Ma, et al	To describe the frequency	Prospective cohort	n=1055 patients ≥ 65	Statistical methods	65.3% of managed care

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures / Data Collection	Findings
(2004)	of inter-institutional transitions after hospital discharge in 2 payment systems	Reimbursement payment system	years transferred from acute care hospital to SNF or IRF in the <u>US</u>	unspecified. patient characteristics, Charlson Index, physical function; mortality In person / telephone interview, medical records, claims data.	patients and 75.6% of fee-for service patients experienced between 2 and 3 transfers in the first 3 months following discharge to SNF/IRF. Transfers declined over the next 9 months in both payment groups.
Boockvar et al (2006)	To examine the effect of pharmacist medication reconciliation on the occurrence of drug-discrepancy adverse drug events among residents returning from hospital to NH.	Pre-post intervention, quasi-experimental design Intervention vs. control	n=168 US NH residents with 259 hospital stays of > 24 hours and returned to the NH.	Multivariate logistic regression; Sum of risk. Intervention: pharmacist medication reconciliation Demographics, hospital & NH LOSs, Charlson (adapted) score, physical and cognitive function from MDS, APACHE scores; Drug Discrepancy Risk Index.	The intervention identified 169 prescribing discrepancies. Physicians responded to 598 (85.9%); 112 cases were selected for ADE ascertainment. Among these, 11 discrepancy related ADEs were identified (10 pre- / 1 post-intervention). After baseline ADE risk adjustment, odds of discrepancy-related ADE were significantly lower in the post-intervention group. Most common: Antibiotics and analgesics.
Boockvar & Burack (2007)	To identify organizational factors and hospital and NH organizational relationships associated with more-effective care-transfer processes.	Mailed survey based on theoretical model of factors that might affect interorganizational transfer of patient care	N=229 Nursing home Administrators from New York State (US)	Pearson correlation coefficients, multivariate regression Structured survey with option for open-ended responses.	There was no relationship between hospital-NH interorganizational relationships and communication, healthcare goal adherence, and satisfaction measures. Geriatric specialty care and

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures /Data Collection	Findings
					fewer hospital beds were each associated with NH's more frequent receipt of all information needed to provide care. Teaching status and geriatric specialty care were associated with hospital care more often consistent with NH established healthcare goals. Organizations with poorer quality records were more likely to have engaged in quality improvement activities.
Kind & Smith (2008)	To examine the completeness of discharge summary documentation in a large Midwestern academic hospital for patients discharged to subacute care facilities.	Medical record review Admission diagnosis	All patients >18 years old (n=266) discharged from a single US hospital to subacute care with 1 of 8 diagnoses.	Consensus methodology was used to operationalize the JCAHO mandates	Reason for hospitalization, significant findings, procedures and treatment provided, and patient / family instructions) were included in 99 to 100 percent of charts Attending physician signature (88-95%) and patient's discharge condition (79 -90%) were provided less frequently.
Ward, et al (2008)	Would a program of employing multifaceted educational strategies be effective for implementation of an expedited medication	Intervention vs. control	N= 20 patients (10 in each arm) ≥65 years being discharged from 1 of the hospitals.	Means, t-test, chi-square Intervention: Modified approach to ensure medication arrival before patient at NH.	Implementation was incomplete. All patients with evening medications missed at least 1 dose of medication. Mean delay from NH arrival

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures / Data Collection	Findings
	order intervention in the transitional care environment?			Demographics, time of NH arrival and first dose of each medication, numbers and types of omitted medications.	to first dose of medication was 12.5 hours (sd 7.45 hours). 33% of the 67 medications missed were considered high-severity; 42% medium severity; 25% low severity.
Karmel, et al (2009)	To describe movement of people from hospital into residential care at national, state, and territory levels (2 additional aims are outside the content of this review)	Event-based linking of administrative databases Hospital discharge destination	n=99,907 admissions into RAC and n=948,200 hospital discharges of over 1 night in <u>Australia</u>	Logistic regression demographics, hospital sector, care type hospital, hospital admission mode, hospitalization length, principal admission diagnosis, presence/ absence additional diagnoses. Large databases.	3.2% of hospitalizations for people over age 65 ended in admission into RAC. 5.5% returned to RAC following hospital discharge.
Lester, et al (2009)	To assess the roles and responsibilities of SNF staff in the transfer process from the hospital to the NH	National survey Percentage of NH respondents	N = 241 <u>US</u> Long term Care NH	Chi-Square tests Voluntary, anonymous online survey	The admission coordinator role is widely used to direct admissions to NHs. Admission nurses consistently had the most responsibility for medication reconciliation. Communication via paper is the norm.
Shah, et al (2009)	[T]o identify perceived barriers to communication between hospital and NH at the time of patient transfer	Mailed survey	N=229 Nursing home Administrators from New York State (US)	Mean ratings of importance, correlation coefficients Structured survey with option for open-ended	Most important barriers to communication were lack of hospital provider effort (51%); hospital providers unfamiliar with patient

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures / Data Collection	Findings
	and examine associations between barriers, hospital and NH characteristics, and hospital-NH interorganizational relationships.			responses.	(45%); lack of hospital provider time (43.5%); transfers on nights or weekends (41.4%); and hospital providers' belief that transfer process is unimportant (38.9%). NHs receiving patients from larger, urban, and teaching hospitals were more likely to report worse barriers to communication. NHs who used hospital services or with cross-site visits by NH staff reported decreased perceived barriers to communication.
Digby et al (2011)	To better understand the experience of the patient with dementia who is settling in after transfer from the acute care hospital to a subacute facility	Qualitative descriptive design Patient themes	N=8 patients with complex needs and mild to moderate dementia transitioned to an <u>Australian</u> geriatric facility for slow stream rehabilitation	Semi-structured interview with of techniques specific to interviewing patients with dementia	Four themes were identified: settling into a new environment, staff attitudes to people with dementia, loss of control, and family support.
Bell, et al (2012)	To develop quality measures for medication continuity among long term care residents for selected medications used to treat chronic diseases with specific interest at point of transition	Delphi study Groups of drugs	Panel of 10 Canadian and international experts selected through recommendation	Modified Delphi consensus technique Basis for selection: strength of research evidence; potential links between processes and outcomes of care;	4 medications were considered important for QI: statins, anticoagulants for treatment of atrial fibrillation, proton-pump inhibitors for post-gastrointestinal hemorrhage, and thyroxine.

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures /Data Collection	Findings
	between long term care and acute care			outcome measures attributable to an individual facility	Consensus was reached on 3 additional drug groups for future research. Prior medication use was defined as 1 year of continuous medication use.
Elliott, et al (2012)	[T]o describe and quantify medication management problems in the 24 hours after discharge from hospital to residential care.	Observational	N=202 patients discharged from an acute or a sub-acute care hospital to residential care facility in metropolitan Australia	Structured phone interview RCF arrival time; updates to RCF medication chart; personnel updating; medications available for first dose; missed or delayed doses; methods of administration and documentation if outside protocols	18.3% of patients experienced a missed or significantly delayed dose; 12% of these were determined to be high risk. Locum doctors wrote or updated medication charts for 32% of patients; 65.2% of these were not completed in time for the first dose. Staff used “workarounds” to administer medications for 57.4% of patients when the usual format was not available. Of reviewed discharge summaries, 83.1% contained a discharge medication list. Of those, 79.7% contained one or more medication or dose discrepancies. Medication administration errors were identified in 20.3% of patients. Representations to the hospital occurred in 7.9% of patients within 7

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures /Data Collection	Findings
					days of discharge. These patients were more likely to have experienced a delayed or missed dose than those who did not represent, but none were directly related to the return.
Burton, et al (2012)	To examine whether physicians recommended venous thromboembolis (VTE) prophylaxis for medical patients at risk on transfer to long term care	Retrospective medical record review Low, medium or high risk for VTE	n=70 patients ≥ 18 years, discharged from general medical service to subacute or long term care in <u>US</u>	Institution-developed VTE assessment tool was used as standard Baseline demographics, length of stay, VTE risk at discharge, type of prophylaxis ordered at discharge, contraindications.	VTE prophylaxis recommendations were not routinely documented for transfer to long term care: 30% (21 Of 70) of patients had appropriate recommendations for VTE prophylaxis. 20% (14 of 70) of patients had contraindications to pharmacology therapy listed.
Kirsebom, et al (2012)	To investigate hospitals and NH RNs experiences of coordination and communication within and between care settings when older persons are transferred from NHs to hospital and vice versa.	Descriptive, qualitative NH and hospital RN themes	N=14 hospital and n=16 NH RNs from Sweden	Focus groups of RNs with similar practice to within group saturation. Content analysis.	NH RNs noted difficulty in decision making regarding when to transfer to the hospital. Hospital RNs reported attempting to stop premature discharges and carrying out discharges that were not fully prepared. Both groups agreed that collaboration and communication should increase.
Zafirau, et al	To examine the effect of a	Pre-post testing of	n=247 patients	Intervention:	Form was used in <50% of

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures /Data Collection	Findings
(2012)	tool designed to narrow the communication gap between long term care facilities and 1 acute care hospital	intervention Intervention vs. control	admitted through the ER in 1 US hospital to inpatient units from 26 long term care facilities	implementation of a new transfer form Primary outcome = whether form accompanied patient Long term care, EMS, and hospital records	transfers. A 66% increase in concordance between documents in LTC and hospital advance directives between pre and post measurements. May have also increased admissions to the acute palliative care unit.
Aaltonen, et al (2013)	To ascertain to what extent care transitions differ between municipalities in the last 2 years of life in Finland.	Retrospective large dataset analysis Individual	N=67,027 residents of Finland age 70 or older who died in 2002 and 2003	Negative binomial regression analysis with median rate ratios. total number transitions, number transitions between home and different care facilities, transitions between different care facilities(2 yrs). 2 large databases.	Municipality had only a minor effect on total number of care transitions. Largest differences were found in care transitions involving specialized care. Individual factors had a statistically significant effect on number of transitions.
Popejoy, et al (2013)	To describe the type and number of transitions and problems experienced by older adults in the year following surgery for repair of a hip fracture.	Qualitative, descriptive, multiple case study Individual	N=21 adults aged 65 and older who underwent hip fracture repair between Sept 2009 and June 2011 in 2 <u>US</u> hospitals.	Multiple case analysis using matrices Demographics, medical diagnoses, Barthel Index, medications, tests, treatments, and plans. Chart abstraction, patient interview	Three patterns of transition emerged: Home to hospital to IRF; home to hospital to SNF; and intermediate NH to hospital to SNF. Patients newly admitted to SNFs experienced more problems and order discrepancies than those

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures / Data Collection	Findings
					discharged to an IRF. Families identified problems first.
King, et al (2013)	To examine how SNF nurses transition the care of individuals admitted from hospitals, the barriers they experience , and the outcomes associated with variation in the quality of transitions.	Qualitative SNF nurse themes	N=27 <u>US</u> SNF RNs	Focus groups and a single individual interview, grounded dimensional analysis.	Written documentation is primary method of communication at transition with multiple information inadequacies, requiring clarifications and creating care delays, increasing staff stress and patient /family frustration, contributing to a negative SNF facility image and increased risk of rehospitalization. A list of needed information is provided.
Reid, et al (2013)	To assess feasibility of (one of 5 objectives reported here) describing the sample of transitions .	Pilot observational study using OPTIC conceptual framework	N=54, Purposive, convenience samples of patients aged ≥65 transferring from participating NHs to a participating ED and returning to NH in 2 Canadian provinces	Percentages. T3 electronic data collection of elements from NH, EMS, ED and disposition, discharge, and return to NH.	The ED summary, inpatient summary transfer record, lab results / orders, patient follow-up and others were not commonly recorded or found in the resident's NH chart upon return. All documentation types were missing most often for the return to the NH.
Sinvani, et al (2013)	[T]o follow patients' medication reconciliation through hospitalization and rehabilitation to measure and classify medication changes that	Retrospective medical record review	N=44 patients' medical records from a single large health system in the <u>US</u> , including hospital, SNF, and home or	Weighted proportions Medical record review of electronic medication reconciliation completed with each	All patients experienced discrepancies. 86% had ≥1 unintentional discrepancy. The average number of medications increased at hospital and SNF admission,

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures /Data Collection	Findings
	<p>occur to assess the effectiveness of the medication reconciliation process as patients transition through a large health system.</p>		LTC.	<p>transition. Measures: Total number of medications; total daily doses; total number of as needed medications; Coleman’s Medication Discrepancy Tool (adapted) with separation of unintentional and intentional discrepancies.</p>	<p>but decreased at discharge to home or LTC. Surgical patients had more discrepancies at admission to hospital and discharge to home. Cardiovascular drugs were the subject of the most unintentional discrepancies (26%).</p>
Caruso, et al (2014)	<p>[T]o determine the number and types of follow-up recommendations... that were completed within 180 days of hospital discharge to a NH and while subjects were in the NH.</p>	Medical record review	N=51 patients ≥65 yo discharged from Boston Medical Center to one of 10 NHs serviced by a single Geriatric Service.	Summary statistics Demographics, length of stay in NH, recommendations made during inpatient stay, completion status of recommendation, reasons for failure to complete.	152 recommendations were made by inpatient providers. Most common: subspecialty referral, laboratory test, and medication changes or monitoring. Of these 24% had no documentation of follow up within 6 months of discharge. 35% documented reasons and 65% did not document reasons for failing to follow recommendations. As the number of recommendations made increased, the number followed decreased.
Popejoy, et	To learn from the nursing	Cross-sectional web-	N=178 NHs from	Tukey-Karmer	NHs indicated no willingness

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures /Data Collection	Findings
al (2014)	facility perspective the challenges faced in transitioning residents to skilled nursing facilities from hospitals.	based survey of healthcare teams in NHs	Missouri (US)	adjustment for multiple comparison; content analysis of short answer questions; Survey = 81 Likert-type and short answer questions regarding willingness to accept; frequency of problems; useful strategies.	to accept patients requiring a ventilator, TPN, or use of a sitter. There were also patient needs and medical conditions that NHs were less willing to accept (e.g., tracheostomy, behavior management problems). Most frequently, cost of care was reported to influence these decisions. Issues viewed as most problematic at transfer included lack of hospital and accepting physician communication, advance health directives not sent, changes to the patient's routine medications, and resident's condition worse than expected on arrival. More than half of NHs very often or often accept weekend admissions. Obtaining signed prescriptions for controlled substances was the only statistically significant problem related to medication / treatment orders. Nearly half of respondents report spending 30 minutes to an

Publication	Purpose ^a	Design / Unit of Analysis	Setting / Sample	Methods / Measures /Data Collection	Findings
					hour reconciling medications on transfer. Nearly half of respondents suggested it would be helpful to speak to a single hospital staff member who was knowledgeable about the patient.

^a Purposes quoted directly from original publications.

Chapter 3: Research Design and Methods

Design

This was a prospective, mixed methods study in which a small quantitative strand was embedded in a qualitative multiple case study design (Creswell & Plano Clark, 2011). Case study is a “detailed, intensive study of a particular contextual, and bounded phenomena that is undertaken in real life situations” (Luck, Jackson, & Usher, 2006, p.104). The phenomenon of interest within this study was care transitions. The case was bounded by the index patient: hospitalized patients over age 65 with advanced chronic illness who planned to discharge into a participating nursing home for skilled care. Informal caregivers (caregivers) and healthcare providers (HCP) associated with the index patient were also included within the case.

The design included intensive study using multiple sources of data. These data sources were: patient, caregiver, and HCP interview, quantitative measures, and medical record review. These data were collected through repeated interactions, both formal and informal during the study period, from hospitalization through 120 days following discharge. Formal interviews were planned using a semi-structured format with patients and caregivers 5 times over the course of study, beginning prior to hospital discharge, within 48 hours of admission to the nursing home, and once per month after. Informal interactions were triggered by events, as well. Formal interviews were held with HCPs initially and were enriched with direct-care HCP interviews during data collection with patients and family caregivers.

The rationale for the duration of study participation was based upon a combination of evaluation of Medicare benefits and review of the literature. Medicare benefits currently allowed for up to 100 days of skilled nursing care. A study of Medicare populations found that between 65.3 and 75.6% of patients experienced 2 to 3 transitions by the third month (Ma, Coleman, Fish, Lin, & Kramer, 2004). Given a boundary of 120 days, a substantial portion within

this study were expected to transition multiple times, providing an opportunity to explore not only the transition from the hospital to nursing home, but also subsequent care transitions that occurred during the period of eligibility for skilled care in a nursing home.

Case studies are appropriate for use with qualitative, quantitative, or mixed methods approaches dependent upon the research questions driving the research (Luck, Jackson, & Usher, 2006). Mixed methods studies such as this include the integration of qualitative and quantitative data collected and/or analyzed within a single study. Within this definition, data may be collected either concurrently or sequentially and one strand may be given higher priority than the other (Creswell et al. 2003/2008, 161--196).

Mixed methods were chosen to enable viewing care transitions in a holistic manner consistent with the theoretical framework, complexity science (Bryman, 2006). Embedded designs are typically chosen when a single data set cannot adequately address the research purpose (Creswell & Plano Clark, 2011) as was the case within this study. Embedded mixed methods designs were used in nursing to evaluate a transitional care program (Ornstein, Smith, Foer, Lopez-Cantor, & Soriano, 2011). An embedded mixed methods design was also used in a study that identified and developed strategies for barriers and facilitators to implementation of evidenced-based practice in nursing homes (Kaasalainen et al., 2010).

Other mixed methods designs have been used within transitions research, as well. Arora and colleagues (2010) completed a convergent parallel mixed methods study of older patients' experiences following hospital discharge alone and in the context of primary care physician awareness of the hospitalization. A study of staff perspectives of avoidability of transfers from nursing home to hospital also used a convergent parallel design (Lamb, Tappen, Diaz, Herndon, & Ouslander, 2011). Nurse researchers are leaders in the use of mixed methods (Plano Clark, 2010).

Relevant challenges associated with embedded designs include the need for both qualitative and quantitative research expertise, the need to clearly state the purpose for collecting the secondary strand, and the difficulty of integrating results when the two methods are used to answer different research questions (Creswell & Plano Clark, 2011). These challenges were addressed within the design and implementation of this proposed study. Specifically, Dissertation Committee members agreed to provide guidance in the collection and analysis of both qualitative and quantitative data. Aims for qualitative, quantitative, and mixing phases of the study were clearly defined and address the overall purpose of the study. Strategies were identified to ensure adequate integration of the data using Visual Graphical Analysis merged with qualitative findings, a technique that has been successfully used by a Committee Member (Schumacher, Plano Clark, & Lydiatt, 2012). Figure 3.1 depicts the study design.

Methods

Settings. Patient recruitment and initial data collection occurred on inpatient units within two hospitals in a mid-western city. One of the hospitals was a large tertiary care, teaching facility. The second was a smaller private facility. Patients were followed after discharge to two participating nursing homes within the same city. Each of these nursing homes had separate skilled nursing units within the facilities. Both nursing homes were part of non-profit organizations, accepted both Medicare and Medicaid payments, and were located in ethnically and racially diverse neighborhoods. While there was variability in overall ratings for the two organizations on the CMS Nursing Home Compare website, at the time of selection, quality ratings for both organizations were above average (Centers for Medicare and Medicaid Services, 2012).

Due to Medicare limitations on payment for skilled nursing care, it was anticipated that many, if not all, of the patients would also transition to a permanent residence by the completion of 100 days of skilled nursing care. Permanent placement following completion of skilled care within each of these facilities would require a transition to another unit, even if the patient were to remain in the nursing home.

HCP recruitment occurred within each of the participating facilities.

Sample. The sample consisted of patients (the index persons), their primary informal caregivers (when one is available and willing to participate), and hospital and nursing home HCPs. Principles of complexity science guided selection of patients with complex, chronic health needs residing in complex environments. The perspectives of patients, caregivers, and HCPs were sought to enable understanding of the dynamic interaction between agents within complex systems. The sample size was determined by the qualitative strand. Participant recruitment continued until data “adequacy,” i.e., until the point that the sample was neither too small nor large (Sandelowski, 1995, p. 179). Upon enrollment of four cases and completion of data collection of a subset, the Dissertation Committee evaluated the adequacy of the sample and determined that four cases provided substantial data that was adequate for the study.

Patients. The study population was purposefully selected for high risk for multiple transitions: adults, age 65 or over, with complex chronic health needs, defined as advanced cancer, stage IV heart disease, chronic obstructive pulmonary disease, stage 3 or 4, or diabetes mellitus in the context of two or more comorbidities. This population is at high risk for readmission (Coleman, Min, Chomiak, & Kramer, 2004; Jencks, Williams, & Coleman, 2009; Ma, Coleman, Fish, Lin, & Kramer, 2004; Mor, Intrator, Feng, & Grabowski, 2010; Weaver et al., 2006) and have complex symptoms requiring management (Gilbertson-White, Aouizerat, Jahan, & Miaskowski, 2011; Hopkinson, 2007; Hwang et al., 2004; Jaturapatporn, Moran, Obwanga, &

Husain, 2010; Maree & Wright, 2008; McMillan & Small, 2002; Parker et al., 2008; Sarna & Brecht, 1997; Spichiger et al., 2011; Tsai, Wu, Chiu, & Chen, 2010; Walsh & Rybicki, 2006). These patients are often dependent upon caregivers as well as HCPs.

Inclusion criteria were: (1) 65 years of age or older; (2) diagnosed with advanced cancer; stage IV heart disease; stage 3 or 4 chronic obstructive pulmonary disease; OR Diabetes Mellitus in the context of 2 or more comorbidities (3) an inpatient at one of the participating hospitals (4) scheduled for admission to a participating nursing home for skilled care; and (5) cognitively intact indicated by being able to state their name, where they are, and to describe what participation in the study would involve, including consequences. This approach is consistent with methods described in the literature for minimum risk studies (Lingler, Jablonski, Bourbonniere, & Kolanowski, 2009). Exclusion criteria were: (1) Non-English speaking and (2) death anticipated by hospital HCPs within the study period.

Informal Caregivers. Caregivers were family members, friends, or neighbors who provided support and assistance over time. A patient could have participated in the study without a participating caregiver.

Caregiver inclusion criteria were: (1) Age 19 or older (the age of majority in Nebraska); (2) identified by patient as his/her primary caregiver; and (3) cognitively intact indicated by being able to state their name, where they are, and to describe what participation in the study will involve including consequences. Exclusion criterion: (1) Non-English speaking.

Healthcare Providers. The HCP sample consisted of two groups. The first group were nurses, physicians, and social workers who had strong experience in care transitions of the target population within a participating facility. This group had expertise in the main study phenomenon, but might or might not have had direct care responsibilities for patient participants. Interviews with this group were for the purpose of exploring the context of care

(Facility-level context). The second group consisted of HCPs with direct care involvement with participating patients (Patient-related) and included nurses, nurse practitioners, social workers, certified nursing assistants, nutritionists, physical therapists, chaplains, and administrators.

HCP inclusion criteria were: (1) 19 years of age or older; and (2) practicing in participating institutions (3) strong experience in care transition of the target population within a participating facility OR direct care responsibility for an index patient.

Facility-level context. Staffing design of the hospital units and nursing homes drove purposeful selection of HCPs with insight regarding the care transition process for the target population within participating facilities. Snowball sampling techniques were used to support enrollment of willing participants. Snowball sampling techniques involve identifying a small number of participants who fit the inclusion criteria, here HCPs with strong experience in care transition within participating facilities, and engaging those participants in identifying additional study participants who meet inclusion criteria (Merriam, 2009). Through this typical qualitative sampling technique, I anticipated recruitment of a HCP sample with rich information. I anticipated that approximately 10 HCPs from each facility would be interviewed to achieve multiple descriptions of care transitions for the targeted populations.

Patient-related. HCPs with direct care responsibility for index patients were interviewed in conjunction with the patient-related data collection. These HCPs were identified through patient interaction and medical record review. For example, nurses identified during medical record review were approached with questions regarding the patient's care.

Attrition. Given the advanced stages of chronic disease in the sample, some attrition was anticipated. Regardless of the attrition rate, patients were enrolled until the data reached "adequacy," consistent with qualitative research methods. Should a patient have become too ill to actively participate in formal interviews or quantitative data collection, the case would have

remained active for 120 days, with data collection through observation, medical record review, and interviews with caregivers and HCPs. Should the patient have died, the case would have been closed. Patients discharged to home or a non-participating facility (and their caregivers) were interviewed once following the transition. HCPs at the non-participating facility were not enrolled in the study, however. These strategies limited attrition so that the study could be completed in a reasonable time frame.

Data collected.

Qualitative Strand.

Facility-level context. Formal semi-structured interviews with HCPs and administrators in the hospital and each of the nursing homes were conducted to learn as much as possible about the context for care transitions within the facilities (i.e., the facility-level context). The interview included perceptions of when and how care transitions occur within the organization as well as policies, procedures, and protocols pertaining to care transitions. Data collection methods and strategies are included in Table 3.1.

Patient-related. Patients, caregivers, and direct care HCPs were engaged through scheduled semi-structured interviews, observation in each setting, and unscheduled informal interaction as salient situations occur. These salient situations, or trigger events, were clinical situations such as a care transition or “near miss” in which an unplanned transition was prevented.

Care transitions and their context were explored broadly to elicit each perspective fully. For the patient and the caregiver, formal, semi-structured interviews occurred prior to hospital discharge, upon admission to the nursing home, and monthly thereafter. These interviews focused on reason for admission, support systems, and expectations for and experience of the

transition. Observation and informal interactions occurred 2 – 3 times per week. Topics of informal interactions were focused on trigger events or topics of participant interest.

HCP informal interactions occurred 2 – 3 times per week and focused on trigger events and/or questions related to medical record review. Occasional HCP formal interviews related to the index patient occurred following a substantial trigger event where the informal interaction would not be adequate. Content of the interview centered on the trigger event.

Formal Interview Guides for each participant and time period are located in Appendix A.

Medical record review. Medical record review captured qualitative data in the form of narrative provider notes and discharge plans and quantitative data in the form of emergency room visits, hospital readmissions, and transfer from skilled care to a long term care bed, or discharge to home, among other. Description of the patients' clinical status over time and the formal treatment plans were abstracted qualitatively from provider notes. These qualitative abstractions included patient discharge instructions for medications and treatments; physician, product and service referrals; and clinical assessments. Changes over time were qualitatively noted.

Consistent with the care transitions definition within this study, each care transition, whether for planned or unplanned healthcare utilization, included the physical move and the planning and coordination necessary to accomplish it. As such:

- An emergency room visit was a physical transfer to any hospital emergency room with or without subsequent hospital admission. An unplanned physician office visit did not constitute a care transition. Such a visit was, however, deemed a trigger event for further qualitative data collection.

- A hospital readmission was an unplanned physical transfer to an inpatient admission within a hospital. Planned admissions for treatments, such as scheduled chemotherapy, were

noted within the qualitative analysis but were not considered unplanned utilization. A hospital readmission that occurred following an emergency room visit was considered as one event, a hospital readmission.

- Any transfer from the skilled facility following completion of care or for planned care was studied qualitatively. These care transitions such as discharge to home or transfer to permanent placement within a nursing home were not considered quantitatively as unplanned utilization.

Quantitative Strand.

While this was a qualitative dominant study, two measurement tools were used in the embedded quantitative strand: The Memorial Symptoms Assessment Scale – Short Form and the McGill Quality of Life Questionnaire. Socio-demographic and medical data were also collected. A list of variables and measurement tools is contained in Table 3.2.

Symptom distress was measured using the *Memorial Symptom Assessment Scale – Short Form* (MSAS-SF). The MSAS-SF was developed from the full MSAS to accommodate the limited energy of patients with advanced disease. The short form measures distress and frequency of 32 symptoms and can be completed in less than 5 minutes. Cronbach's α for the subscales (global distress index, physical symptom distress score, and psychological symptom distress score) ranged from 0.76 to 0.87, indicating acceptable reliability. The MSAS-SF was found to be valid for use with cancer patients (Chang, Hwang, Feuerman, Kasimis, & Thaler, 2000) and end stage heart disease (Tranmer et al., 2003). Use in advanced cancer (Bausewein et al., 2010; Hwang, Chang, Fairclough, Cogswell, & Kasimis, 2003; Hwang et al., 2004; McPherson, Wilson, Lobchuk, & Brajtman, 2008; F. E. Murtagh et al., 2010) and heart disease (Bekelman, Dy et al., 2007; Bekelman, Havranek et al., 2007; Bekelman et al., 2009) has been documented. The MSAS-SF is contained within Appendix B.

The MSAS-SF measures the presence of and distress associated with 26 physical and 4 psychological symptoms. The instrument requests the patient's assessment of the presence of the symptoms over the last 7 days. Number of symptoms is the count of present symptoms. Distress for present physical symptoms is measured on a 5-point scale from "not at all" (0.8) to "very much" (4.0). Distress for psychological symptoms is measured in terms of frequency of symptoms from "rarely" (1) to "almost constantly" (4). Sub-scales are the global distress index including 4 psychological symptoms (feeling sad, worrying, feeling irritable, and feeling nervous) and 6 physical symptoms (lack of energy, pain, lack of appetite, feeling drowsy, constipation, and dry mouth); the physical symptom distress scale which includes 12 prevalent physical symptoms (lack of energy, pain, lack of appetite, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness); and the psychological symptom distress scale which includes 6 prevalent psychological symptoms (worrying, feeling sad, feeling nervous, difficulty sleeping, feeling irritable, and difficulty concentrating) (Chang, Hwang, Feuerman, Kasimis, & Thaler, 2000). Scores for the sub-scales are the means of distress associated with each of the included symptoms (Bausewein et al., 2010).

Quality of life was measured with the *McGill Quality of Life Questionnaire* (MQOL), a 17-item questionnaire designed to assess quality of life (QoL), or "subjective sense of wellbeing." Construct validity has been demonstrated in comparison to both a single-item measure of QoL and the Spitzer Quality of Life Index (Cohen, Mount, Strobel, & Bui, 1995; Cohen, Mount, Tomas, & Mount, 1996; Cohen et al., 1997; Cohen & Mount, 2000; Cohen, Boston, Mount, & Porterfield, 2001; Cohen & Leis, 2002). Internal consistency of the complete questionnaire and the sub-scales is strong with Chronbach's α ranging from .73 to .84. The physical symptoms sub-scale consists of identical items which ask the respondent to identify their 3 most troubling symptom or problems and to indicate the degree to which the symptoms have decreased QoL. The lower

Chronbach's α (.62) for this sub-scale was anticipated due to the structure of these questions (Cohen et al., 1997). Test-retest reliability has been shown in cancer patients. Intraclass correlation coefficients were found to be between .62 and .85 (Cohen SR & Mount, 2000). Responsiveness to change was also demonstrated using patient ranking of "good", "average," or "bad" days. ANOVA tests with post hoc analysis indicated a significant difference between day types for all scores and sub-scores other than support (Cohen SR & Mount, 2000). The MQOL is contained within Appendix B.

The MQOL requests the patient's response to statements using a scale (0 – 10) of extreme responses (e.g., very bad to excellent) over the past 2 days. Although some of the questions required transposing, the instrument is reported with all lower responses indicating lower QoL and higher responses indicating higher QoL. A global measure, four subscales and two single item subscales (SIS) are included within the MQOL. The Global MQoL was calculated from the means of the four subscales and the physical well-being SIS. The Physical Symptoms subscale is the mean of the (transposed) scores for "physical symptoms or problems" identified by the patients. Patients were asked to identify up to three physical symptoms or problems. The Psychological Symptoms subscale is the mean of four items, all transposed, related to "feelings and thoughts" over the past two days. These questions ask about the experience of feeling depressed, nervous or worried, and sad, as well as the patient's thought of the future. The Existential subscale is the mean of six items. These questions (items 9 – 14) ask for the patient's thoughts on such topics as control. The Support subscale is a two-item scale of support and responsiveness (items 15 and 16). Two single item responses are also included: the Physical well-being subscale (item 4) and the MQOL-SIS. (Cohen, Mount, Tomas, & Mount, 1996) .

Socio-demographics and medical data, where possible, was collected using chart review and confirmed with the patient and / or caregiver to ease burden of data collection. Socio-

demographic variables included were: age, gender, marital status, education, race / ethnicity, education, hospital / nursing home payment source (e.g., Medicare, Medicaid, Long Term Care insurance, etc.), location of residence, and length of time at residence. Caregiver socio-demographic variables included age, gender, marital status, race / ethnicity, education, relationship to the index person, and location of residence. HCP demographics included age, gender, race / ethnicity, education, professional role, professional certifications / licensures, years of experience, and years in current role. In each of the samples years in residence, years of experience, and years in current role were collected as continuous variables. All others were collected as categorical variables.

Medical data were collected for index patients. This data included primary diagnosis and co-morbidities; the hospital admitting service and physician, specialty and number of physicians engaged in the patient's care before and during the hospitalization. No personal identifiers were collected on these professionals. Tools for collection of Socio-demographic and medical data are included in Appendix B.

Procedures.

Participant Enrollment and Informed Consent.

Patients. Patients were evaluated for eligibility by social workers from the hospital inpatient units and nurse intake coordinators from the nursing homes who were trained regarding the content and inclusion criteria of the study. These professionals introduced the study and gained permission for the PI to visit the patient and caregiver to explain the study and obtain consent from those willing to participate. Findings of a preliminary study completed during the fall of 2011 indicated the feasibility of recruiting patients in this manner.

Healthcare provider. Prospective subjects were identified through the management and administration of each of the participating facilities, hospital and nursing home.

Facility-level Context. Each of the facilities agreed to provide access to HCPs with knowledge and experience related to care transitions from hospital to nursing home and beyond. Management and administration obtained permission from potential HCP participants for the PI to contact them. Snowballing techniques were used to identify additional HCPs with strong knowledge of care transitions within each facility. Every eligible HCP was considered for the study, regardless of gender, race, or ethnicity.

Patient-related. Each of the facilities agreed to facilitate access to HCPs providing direct care to the index patient. Prior to consent of the first patient, the PI addressed the SNF unit within the first nursing home to consent HCPs with responsibilities on the participating units. Within the second nursing home, the PI addressed management who privately introduced the staff on the units. Any additional HCPs with patient care responsibilities, including those on hospital inpatient units, with index patients were approached for consent prior to interview.

Data Collection Procedures.

Qualitative Strand.

Healthcare provider.

Facility-level Context. Following attainment of consent, HCPs were interviewed at least once in a private location within the facility such as an office or conference room. It was estimated that each interview would require no more than 1 hour of the HCPs time. If necessary these interviews were divided into shorter periods.

Patient-related. Informal interactions with HCPs providing care for participating patients occurred intermittently during the study. These casual conversations were anticipated to last 5 – 10 minutes 2 – 3 times per week at the HCP's convenience. Formal interviews were to be requested to discuss trigger events. These semi-structured interviews were scheduled with the HCP's agreement and at their convenience.

Separate formal interviews with patients and caregivers were requested prior to hospital discharge, at nursing home admission, and at least once per month after. It was estimated that each patient and each caregiver interview required no more than 1 hour of the participant's time. If necessary, these interviews were divided into shorter periods. Interviews prior to hospital discharge took place on the inpatient unit. Subsequent interviews usually took place in the nursing home. However, for patients and their caregivers who transitioned to another setting during their study participation, one follow-up interview took place in the new setting, or in a mutually agreed location such as the participant's home, a second facility, or a public location of the participant's choosing.

The PI was present in each setting at least 2-3 times per week to check on patients, and to participate in rounds and care planning meetings for participating patients. This regular presence allowed her to capitalize on serendipitous opportunities. When an observation indicated the need for additional information, brief, informal interactions occurred. "Trigger events" that prompted an informal interaction included a care transition or "near miss" in which an unplanned transition was prevented. These informal interactions occurred, with the patient's and caregiver's permission, approximately weekly for 15 minutes. These were unstructured casual conversations at the patient's and caregiver's convenience. Observation data, recorded in field notes, were ongoing in each setting. Medical record reviews occurred at least every two weeks.

Caregivers were invited to participate along with the patient. Their involvement was similar to that of the patient, e.g., they were involved in a series of 5 formal interviews. The caregivers' interviews were anticipated to require approximately one hour.

For patients whose caregivers did not wish to participate or for patients without caregivers, I interviewed only the patient for the requested information.

Medical Record Review. Medical record review occurred daily prior to hospital discharge, upon admission and at least every two weeks thereafter. Qualitative field notes were noted and events such as emergency room and inpatient admissions were collected quantitatively, as well.

Quantitative Strand. The quantitative strand included measures of symptom distress and QoL as described earlier. These instruments were administered by the PI at the same time points as the formal interviews. Socio-demographic and medical data were collected once following enrollment.

Data Management.

Semi-structured interviews were recorded digitally and transcribed in their entirety. Observation, informal interactions, and qualitative medical record data were recorded in field notes. The quantitative questionnaire data and medical record data were electronically entered by the PI on-site.

With subjects' permission, formal interviews were digitally recorded. If a subject requested not to be recorded, field notes were used. All formal interviews from each participant (patient and caregiver) were transcribed verbatim by a transcriptionist who completed human subjects training and signed a confidentiality agreement. After the transcriptions were verified for accuracy, the digital recordings were erased. Observations during the interviews were recorded in de-identified field notes. The same process was used with HCP formal interviews both within the facility-level context (≥ 1 interview for up to 10 HCPs) and the patient-related (as needed and agreed to only) portions of the study. Medical record data and demographic information were recorded on abstract forms. All data were scanned into password-protected electronic files.

Data were linked to subjects by a study-specific ID code number only. Each subject was assigned an ID code for use on all study materials. The only link between a subject's name and ID code was the consent form. One copy of the consent form was kept in a locked file separate from other study materials. Only the PI knew the names, telephone numbers, and addresses of subjects. The PI kept this identifying information only as long as needed to contact subjects. This information was then destroyed. All study materials were kept in locked file drawers in a locked research office or on password protected network drives accessible only to the PI.

All collected data and records were for research purposes only.

Data Analysis.

Aim 1. Qualitatively describe care transitions experienced over time by older adults with complex healthcare needs from the perspectives of patients, caregivers, and HCPs.

Data analysis occurred concurrently with data collection. A "case" consisted of all data relevant to the index patient.

(1) HCP formal interviews regarding care transitions context within the facilities were analyzed to establish the facility-level context for care transitions. This description of care context provided an overview of care transition process, policy, procedures, and roles/responsibilities for each facility. Cultural descriptions both within each nursing home and hospital individually and in interaction together were also described.

These facility-level findings provided a context for analysis of individual cases.

(2) Individual and cross-case qualitative analyses were completed for the patient-related data. Findings from the facility-level context were included in each case as the context of care.

First, data for each patient was read in its entirety (i.e. facility-level context, transcribed interviews, and field notes) and chronological graphical displays inclusive of each perspective

were developed. Graphical representations of the dynamic interactions in care transitions were developed. Case summaries described the care transition(s) experienced by each patient from each perspective. Care was taken to describe the nature of the setting and dynamic interactions at each data collection point.

Coding, categorization, memo-writing, graphical displays and tables were used to move the qualitative analysis to a more conceptual level (Corbin & Strauss, 2008). Concepts, definitions, and descriptions were developed and refined. Initially, data from each source and each time point in a case were coded and categorized separately. Later, graphical data displays were used to integrate the analysis across individual perspectives and time. (Miles & Huberman, 1994). Integration of the data across time in this way facilitated identification of patterns in transition experiences.

Aim 2. Quantitatively describe patient symptom distress, QoL, and selected indicators of unplanned health services utilization (i.e., emergency room, hospital readmissions) over time.

Aggregate descriptive statistics for all variables were calculated, including means and standard deviations. Trajectories of change in QoL and symptoms were plotted graphically for each individual and emergency room visits, readmissions, and other transitions were superimposed. Visual graphical analysis was used to identify similarities and differences in trajectories and healthcare utilization across cases. Visual graphical analysis (Brown, McGuire, Beck, Peterson, & Mooney, 2007) is especially useful for displaying change over time when a qualitatively-driven mixed methods sample is too small for inferential statistics. This method has been used in research to show trajectories of symptom and disease progression in cancer (Bausewein et al., 2010; Brown, McGuire et al., 2009; Brown, Beck et al., 2009) and chronic progressive disease (Bausewein et al., 2010; Lazic, Mason, Michell, & Barker, 2009; F. E. M. Murtagh, Sheerin, Addington-Hall, & Higginson, 2011).

For the MSAS-SF, each physical symptom was measured based on its presence and on the severity of distress associated with it, when present. When a symptom was not present, it was scored as 0. When present, distress was scored on a 5-point Likert scale with a range from 0.8 – 4 (not at all, 0.8; a little bit, 1.6; somewhat, 2.4; quite a bit, 3.2; very much, 4.0) for physical ratings. For psychologic symptoms, a standard Likert scale was used, as was recommended in the literature. Frequency of psychologic symptoms was scored rarely (1), occasionally (2), frequently (3), or almost constantly (4). Three sub-scales were calculated from the MSAS-SF. The Global Distress Index (GDI) is calculated from means of 4 psychologic symptoms (feeling sad, worrying, feeling irritable, and feeling nervous) and 6 physical symptoms (lack of energy, pain, lack of appetite, feeling drowsy, constipation, dry mouth). The physical symptom distress score is calculated from the means of 12 physical symptoms (lack of energy, pain, lack of appetite, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness). The psychologic symptom distress score is calculated from 6 psychologic symptoms (worrying, feeling sad, feeling nervous, difficulty sleeping, feeling irritable, and difficulty concentrating).

McGill QoL subscales were calculated as described in the literature (Cohen, et al 1997 and Cohen and Mount, 2000). The MQOL SIS, three physical symptoms, and four psychological symptoms measures were transposed to ensure that responses indicated 0 representing the least desirable and 10 the most desirable response. The MQoL was reported using seven measures as described earlier.

Unplanned utilization was calculated from data collected in both qualitative and quantitative sources. Day 0 for each patient was their transition from the index hospitalization to the index SNF. Each patient was considered in only one location per day. For example, on the day that the patient moved from hospital to the SNF, the day was noted as within the SNF.

Unplanned hospital admissions were evaluated for timing and for clinical necessity. Readmissions occurring within 30 days of hospital discharge were described in terms of timing related to the initial and, where relevant, most recent hospitalization. Using the Criteria for Clinical Necessity 30-day readmission at the time of the patient's presentation, readmissions were described in terms of clinical need for the care transition (Hechenbleikner et al., 2013). See Table 3.3 for a description of the criteria.

Aim 3. Better understand patterns in the complexity of care transitions using cross-case comparisons in which each case includes both qualitative patterns and quantitative trajectories of symptoms distress, QoL, and unplanned health services utilization over time.

Qualitative and quantitative findings were merged for cross-case pattern identification and analysis. For this mixed methods aim, cross-case analysis was used to identify commonalities and differences in patients' experiences of care transitions through writing of analytic memos and diagrams (Creswell & Plano Clark, 2011; Creswell, 1998). Through memos and diagrams, I integrated the individual trajectories resulting from Aim 2 with the qualitative patterns discovered in Aim 1. Then, cross-case comparison of two cases purposely selected to represent extremes in principals' care transition experiences was used to identify commonalities and differences in patients' experiences of care transitions from a complexity science perspective. This cross case comparison offered the opportunity to further evaluate differences found in QoL and symptom distress. Also consistent with complexity science, cross-case analysis was used to illuminate the differences in context related to outcomes.

Validity.

Within the qualitative strand of the study, multiple sources of data were collected to provide varied perspectives on care transitions within each case. Patients, caregivers, and HCPs were formally and informally interviewed and observed in addition to data collected from the

medical record. Throughout data collection, verification procedures were used to enhance the validity. Finding the “validity of data observed” (Stake, 1995, p.108) is dependent on methods of triangulation. Within this study, methodological triangulation was used to develop an understanding of the phenomenon of care transitions that is both broad and in-depth. This triangulation was based upon multiple interviews with multiple participants and in concert with medical record reviews. Throughout, discrepancies were probed for further meaning within and across cases.

In the context of dissertation study, confirmatory review by at least two members of the Dissertation Committee occurred at each stage and within each strand of the study as well as within the mixing of the data.

Within the quantitative strand of the study, validity and reliability of the instruments has been addressed within the discussion of measures. Analysis of the quantitative measures using Visual Graphical Analysis has also been discussed. Use of these appropriate measures and analysis tools were supportive of quantitative validity within the study.

During merging of the patient-centered data, all participant data were included in relation to the index patient. Aims within the quantitative and qualitative strands were related and connect to the index patients over the same timeframe. Divergent findings were reported and resolved, when possible.

Human Subjects.

Risks to Human Subjects. This was a minimal risk study, in that the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered during the performance of routine clinical assessments or tests. However, there were psychological risks that might accompany the data collection procedures. The main risk was that patients, caregivers, and HCPs might have found

repeated waves of data collection burdensome. The potential risk of data collection burden was minimized by curtailing the interview if a subject requested to do so or appeared fatigued to the interviewer. Interviews were conducted during more than one shorter sessions, as needed. Also, subjects had the option to withdraw from the study at any time. It was possible that some subjects might have found the interview or questionnaires too personal or that they may become upset or uncomfortable during the interview. If this occurred, the PI would have stopped the interview and emotional support would have been provided by the PI. If follow-up for emotional support was deemed necessary, the patient's HCP, as appropriate, would have been notified of the patient or caregiver's distress (with their knowledge). Referrals to psychologists, psychiatrists, and social workers were available in each participating site, had they been needed. Should a HCP have needed additional support, resources through facility Employee Assistance Programs would have been identified.

There was a risk of loss of confidentiality. Every effort was made to maintain the confidentiality of study materials including primary materials and transcripts through use of study identifiers that were not associated with any personal identifier and maintenance of data within locked and/or password protected locations. Reporting of findings was done in such a way as to protect the identities of all subjects, as well.

There was also the potential that the PI would identify a risk to the patient in the context of observation of care. Should the PI, a registered nurse, have recognized a situation as unsafe or care below acceptable standards, legal and ethical measures would have been taken to protect the patient. For example, if a patient were to have been found in an at-risk situation such as attempting to get out of bed in an unsafe manner, facility nursing staff would have been notified. If, however, broader issues of patient care, such as ongoing unacceptable hygiene, or in

the unlikely event of poor care quality with potential legal implications, the Dissertation Committee would have served as a source of guidance.

The potential risk of psychological discomfort was minimized by assuring participants that they could decline to answer any question or stop the interview at any time. The interviewer was be alert to signs of impending emotional distress and if necessary, would have suspended or stopped the interview and dealt with the distress as appropriate, based on her clinical experience. When indicated, the interviewer suggested that subjects seek additional support or counseling from the staff (physician, nurse, social worker) in their primary care setting for patients and caregivers and Employee Assistance Programs for HCPs. Extreme psychological distress would have been reported to the patient's primary care physician or nurse with the subject's knowledge.

Subjects were advised that they could call the PI at her office after the interview if they became concerned or distressed in response to either the interview or the questionnaires and felt the need to talk about their feelings. See Appendix C for documents related to IRB approval.

Resources.

The major resource required in the completion of this study was the PhD student and faculty time and skill. Faculty who supported the study have experience in nursing research in transitions, nursing homes, complexity science, and using mixed methods.

This research was supported by NINR of the National Institutes of Health under award number 1F31NR013596-01A1. This grant partially supported tuition and provided salary and expense reimbursement to the student. Transcription services was the most significant expense within the completion of the study and was be included in expenses.

Timeline.

Data collection began in the Fall of 2013 following completion of comprehensive exams and obtaining IRB approval and continued through the summer of 2014. Analysis, although begun concurrently, continued through 2015.

Summary

This innovative study of patients with advanced chronic disease using an embedded mixed methods design aimed to achieve a better understanding of care transitions from the perspectives of patients, caregivers, and HCPs.

Figure 3.1: Hospitalized Older Adults' Care Transition

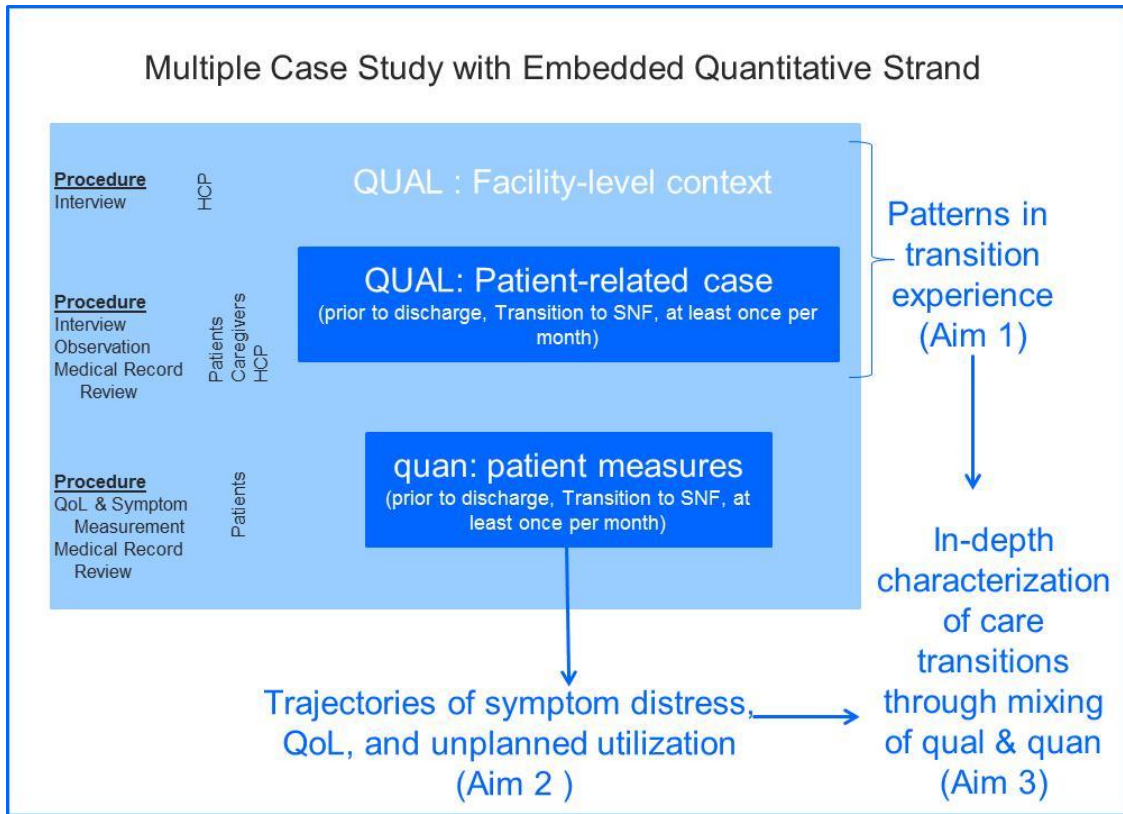


Table 3.1: Data Collection Procedures

Strategy	Sample	Timing	Analysis
Semi-structured formal interviews	HCP	At least once	Facility-level context
	Patients / caregivers	Before hospital discharge, on nursing home admission, and, and once a month thereafter	Qualitative analysis using graphical display; descriptive summary; coding, categorization, memo-writing, and tabular display
Observation & Informal interactions <ul style="list-style-type: none"> • Hospital and SNF patient care units • Index patient care planning & rounds meetings 	Patients, caregivers, HCP	2 – 3 times per week	Qualitative analysis, as above.
Medical record review	Patients	In hospital, daily until discharge In nursing home, ≥ approximately every 2 weeks.	Qualitative analysis, as above Descriptive statistics Visual graphical analysis
Quantitative Instruments <ul style="list-style-type: none"> • McGill QoL Questionnaire • Memorial Symptom Assessment Scale – Short Form 	Patients	Before hospital discharge, on nursing home admission, and, and once a month thereafter	Qualitative analysis, as above Visual graphical analysis with healthcare utilization data superimposed

Table 3.2: Study Variables and Measures

Measure	Variable
<i>Patient</i>	
Demographic questionnaire	Age
	Gender
	Marital status
	Race/ethnicity
	Education
	SNF / nursing home payment mechanism
	Length of time in residence
McGill Quality of Life	Physical well-being scale
	Physical symptoms scale
	Psychological symptoms scale
	Existential scale
	Support scale
MSAS-SF	MQoL - Total
	Number of symptoms
	Global distress index
	Physical symptom distress score
	Psychological symptom distress score
<i>Caregiver</i>	
Demographic questionnaire	Relationship to patient
	Age
	Gender
	Marital status
	Race/ethnicity
	Education
<i>HCP</i>	
Demographic questionnaire	Age
	Race/ethnicity
	Gender
	Education
	Professional role
	Professional certification
	Years professional experience
	Years in current role

Table 3.3: Criteria for Clinically Necessary 30-day Readmission

Major Criteria	Minor Criteria
ICU admission	Abnormal vital signs (temperature $>38.3^{\circ}$ or $<36^{\circ}$ C; tachycardia ≥ 110 bpm, absolute hypotension systolic blood pressure <90 mmHg, clinical documentation of orthostatic hypotension)
Unplanned return to the operating room	Acute renal failure (0.5 mg/dL increase in serum creatinine from a baseline of ≤ 1.9 mg/dL 1.0 mg/dL increase from a baseline of $2.0 \leq 4.9$ mg/dL 1.5 mg/dL increase from a baseline of ≥ 5.0 mg/dL)
Non-operating room invasive procedure	White blood cell count $>12,000$ or $< 4,000$ cells/mm ³
Peripherally inserted central catheter	Severe electrolyte imbalances or hypoglycemia requiring treatment
	Drop in hemoglobin count requiring blood transfusion
	CT scan evidence of bowel obstruction or anastomotic leak
	Bowel obstruction requiring nasogastric tube placement or parenteral nutrition

Chapter 4: Results

Sample description

The sample consisted of four cases plus 30 expert healthcare providers (HCP) who shared information about the study's organizational contexts. Each case consisted of an older adult with advanced chronic illness, the principal figure in the case ("principal"), plus direct care HCPs involved with the principal. A total of 15 direct care HCPs participated as part of the cases. Two cases also included formally consented family caregivers who were interviewed. Other family members were aware of the study and agreed to observation by the PI, but did not formally enroll or participate in interviews. The cases took place within multiple facilities. Two hospitals and two skilled nursing facilities (SNF) formally participated in the study and provided data about their approaches to care transitions. In addition, principals were admitted to other facilities that were not formal study sites. These other facilities included an emergency room, a nursing home, and a long term acute care hospital.

The four principals were between 65 and 94 years of age and identified as Caucasian. All were from a mid-western city with education ranging from less than high school to completion of a bachelor's degree. Two principals were widowed, one single, and one married. Each principal was experiencing multiple advancing chronic illnesses. These illnesses included: diabetes (3), chronic obstructive pulmonary disease (2), congestive heart failure (2), chronic renal failure (2), and hypertension (3), among others. Effects of advancing chronic illness included lessened stamina in activities of daily living; reduced resiliency for stressors such as viral illness; poor vision; reduced peripheral sensation; and incontinence; among others. All of the principals lived in their own homes prior to the initial hospital admission and all were in contact, whether in a social or caregiving context, with family members. None of the principals

identified non-family caregivers. Each of the principals remained cognitively able to participate. See Appendix D for Case Summaries.

All family caregivers agreed to observation within multiple contexts during the study. As noted above, two family caregivers consented to participate in interviews. These were both female over age 40 and identified as Caucasian. Neither was employed outside the home, but both held family responsibilities beyond care of the principal. Family caregiver typical engagement with the principal ranged from phone calls each week to physical and supportive care with the principal multiple times per week.

All of the participating facilities used traditional models of care. None espoused person-centered care. Although medical home models may have been in place, none of the principals entered hospital care within such a model. Likewise, neither nursing home used transitional care approaches.

Consented and interviewed HCPs, totaling 45, were employed in one of the four participating facilities. Forty of the 45 participants were female and 39 identified as Caucasian, five were African American, and one biracial. See Tables 4.1 and 4.2.

Qualitative findings

Aim 1. Qualitatively describe care transitions experienced over time by older adults with complex healthcare needs from the perspectives of patients, caregivers, and HCPs.

Although the intent of the study was to characterize multiple care transitions, the narrative data indicated that care transitions occurred in the context of ongoing life transitions as the principals dealt with the effects and the meaning of aging with advancing chronic illness. Principals and families vividly described the importance of their life transitions which began

before the index hospitalization and continued throughout each case. These life transitions narrowed possibilities, threatened the principals' sense of normalcy and individuality, and challenged the families' abilities to support.

Ongoing life transitions were punctuated by multiple care transitions. Care transitions were HCP-centered processes guided by facility best practices and regulatory requirements. These processes of planning, coordination, and movement from one care setting to another were bounded to the episode of care. Care transition processes promoted patient safety and maintained facility level of care requirements during the episode, but held little meaning for the principals and their families. Principals and family caregivers complied with care transitions, but life transitions dominated their concerns. Therefore, care transitions took place in two important contexts: the ongoing life transition that held great meaning for the principals and their family and the organizational and practice contexts of healthcare facilities and HCPs that served as boundaries for professional roles and responsibilities (facility-level context).

Care transitions and life transitions were interrelated for principals and family caregivers. Aging with advancing chronic illness precipitated the life transitions as the principals and their families struggled to manage effectively at home. The effects of the life transitions shaped principal and family caregiver decision-making for care transitions. Likewise, the multiple care transitions influenced thinking regarding ongoing life transitions. Unlike principals and family caregivers, HCPs were often focused solely on the care transition. Although HCPs were typically aware of the effects of the life transition, they rarely appreciated its meaning to the principal.

The dynamic interaction between principals, family caregivers and HCPs connected the longer term life transitions to the episodic care transitions. This dynamic was heavily influenced

by the multiple perspectives of the players. Principals, family caregivers, and HCPs were at times in accord regarding the principal's care needs. However, at other times, perspectives were widely divergent, with HCPs often unaware of the full meaning of the life transition to the principal and family caregivers. Dynamic interaction between principals, family caregivers, and HCPs offered the potential to open discussion that revealed the life transition and a longer term view of the principal's interests and hopes to the HCPs. Family approaches to supporting the principal and patterns of dynamic interaction between principal, family caregivers, and HCPs had everything to do with whether or not this potential was realized.

Within these qualitative results, I will describe the dynamic connections between life transitions and care transitions. First, I will provide a description of the facility-level context. Second, I will describe the life transitions as experienced by the principals and families. Third, I will consider the multiple care transitions within these four cases from the perspectives of HCP, principals, and family. Finally, I will describe the dynamic interactions between principals, family caregivers, and HCPs within the care transitions.

Facility-level contexts. Of the two contexts for care transitions, facility-level context and life transitions, the former is considered first. This facility-level context provided the HCP norms within care transitions and framed the principal and family experiences.

Thirty interviews were conducted with HCPs expert in care transitions within four facilities, two hospitals and two nursing homes with SNF facilities. From these interviews plus observations within the facilities, an understanding of the care management norms and procedures emerged. Although the focus of the study is care transition as a process including planning and coordination, HCPs spoke of patient admissions and discharges. This language reflects a reality in practice: boundaries set by admissions and discharge do not allow practicing

HCPs a view of the care transition as a whole. This is a distinct discrepancy between practice and research. Within this section, HCP language is used to more accurately reflect the HCPs' approach to the care transitions.

In interviews with HCPs expert in care transitions in the hospitals and in the SNFs, individuals described the norms within care transition from hospital to SNF. These norms were their practices and expectations during planning for care transitions within their daily practice. Although HCPs denied the existence of formal policies and procedures guiding their practice, there were substantial similarities across facilities related to best practice expectations and regulatory requirements.

Hospital context. Within the two hospitals, clinical care and care management responsibilities were managed by separate HCPs. Care managers were service-based nurses who focused on the management of care through discharge. Care managers met with patients typically within 24 hours of hospital admission to assess potential concerns at discharge. Care management HCPs were organized in a clinical service-focused structure. The service-focus supported understanding of typical needs within the populations and common practices within clinical care. Care managers described their practice approaches in terms of the patient population. For example, differences were seen between oncology care manager practices where treatment protocols called for multiple admissions in the course of treatment and surgical services where the interaction consisted of one admission.

Care managers and social workers responsible for managing discharges in the hospitals coordinated workload together. The care managers focused on interacting with the clinical care teams and scheduled medical appointments post-discharge. Care managers worked with the clinical care teams, the principals, and families up to the point of determining that SNF

placement would be needed. This coordination included formal, scheduled meetings with either nursing or medical service providers. Neither of the hospitals had formal processes that included both nursing and medical staff with the care managers. Rather, coordination between nursing and medical teams were managed within separate structures. In both hospitals, care managers shared learning from formal clinical care meetings with the social work staff. Social workers, when consulted, focused on coordination outside the facility. All of the discharges to SNF were managed by hospital social workers.

Hospital care manager and social worker knowledge of nursing homes and their SNF services was limited to the information that they needed to be able to appropriately place patients. Key considerations included requirements for Medicare reimbursement of the SNF stay. For example, a minimum length of hospital stay was required for Medicare coverage of the SNF stay. The hospital care managers and social workers were also acutely aware of the limitations of nursing homes. For example, the social workers knew which facilities were unable to accept bariatric patients, tracheostomies, or high cost medications.

Hospital HCPs had various perspectives on “success,” but all considered “success” to be related to care completed within their facility or lack of readmissions. Nursing staff who focused on care within their facility described success in terms of patient and/or family knowledge of and agreement with the discharge plan. Social workers described success in terms of patient acceptance into their requested facility. Other HCPs, both nurses and social workers, focused on success in communicating with the SNF regarding the patient. Others identified success as avoidance of a readmission. “When it comes to skilled care, success for me is measured in they didn’t return for something that could have been prevented.”

Hospital HCPs saw their role as limited to the “nursing home door” and their knowledge of nursing home practices was limited. A hospital social worker explained her description of what patients could expect in the transition: “I typically just go from the hospital to the nursing home. Because I really don’t know, I’m not the expert on the nursing home side. I don’t know what happens when they arrive there.” None of the hospital HCPs described having knowledge of the nursing homes that they transferred patients to. Those who had visited ANY of the local facilities had only visited one or two.

Hospital HCPs acknowledge little to no feedback following care transition. “We don’t generally know how the skilled nursing turns out. You know, I don’t know if the patient got to go home or if the family’s experience, if they went home and they didn’t come back in, you know, I don’t know if they had a good experience there or not, because we don’t do any follow up.” More importantly, the care managers and social workers note that they do not get feedback on their work in the transition. “The problem is that we don’t get any follow up with patients after they leave to tell us how we did. We have our little survey that we get and our transition score is lower than we would like, so obviously we need to be doing something different, but we don’t know what that is.”

Broad hospital processes were quite similar across service lines and facilities. The process began with a care manager interview soon after hospital admission to identify issues or concerns with returning to the patient’s home. If problems were identified, such as a clear barrier to returning home, a social worker would be called in to begin working with the patient immediately. More typically, the care manager would continue to follow the patient through the clinical course during formal meetings. During these meetings, the care manager would learn of impending discharges and more recently assessed discharge needs. Once SNF admission was imminent, the social worker would meet with the patient and/or family to determine a “list” of

requested nursing homes for SNF placement. While no HCPs offered insight into the quality of care in specific nursing homes, they did share locations and knowledge of insurance network affiliations. They also encouraged families to visit nursing homes before adding them to their lists. Social workers shared that “pretty” nursing homes often could not accept all of the patients who requested them. Social workers asked that patients also include older facilities in their lists, as well. Nursing home admission coordinators would reach back to the hospital social workers to communicate interest and to request additional information. Following nursing home acceptance, the patient and family would choose from those available and transportation arrangements and discharge communications with the nursing home would occur. Typically, from initial patient conversation regarding SNF transition to actual transfer was described as 24 – 48 hours.

The hospital context, then, was driven by best practice norms that were largely consistent across facilities. Separation of clinical care and care management roles focused responsibilities for the HCPs. HCP knowledge, feedback, and focus remained on care within the hospitals. Although care management staff were introduced within 24 hours of patient admission, detailed planning typically occurred within 24 – 48 hours of discharge. Transitions were largely considered successful based on internally focused measures such as adequate communication with the patient, family, and SNF HCPs, for example.

SNF Context. SNF acceptance and admission processes were more variable than the hospitals, but remained largely level of care focused. Distinct differences between levels of care regulation and practice provided for a unique SNF context. While their focus remained on ensuring quality care, they were also concerned about accepting patients with characteristics that allowed for financial success.

Balancing the financial potential with the clinical needs and facility strengths was considered critical. Both facilities spoke of the need to manage the workload for direct care staff. This was considered in terms of staff satisfaction and risk of turnover, but also in terms of financial implications of overtime. Therefore, the admission coordinators looked to the individual referral to determine that their care needs fit within the facility knowledge and skills. The admission coordinators also tried to understand the current workload on each unit to ensure that care of the whole did not extend beyond staffing levels.

Nursing home admission coordinators described important responsibilities for facility success. One admission coordinator described this as “we work hard at breaking even.” Both of the nursing homes within the study balanced a substantial long term care Medicaid population with Medicare SNF populations to ensure financial sustainability. In looking at referrals, the admissions coordinators balanced a number of important clinical and financial criteria: insurance coverage and assurance that all regulatory hurdles were met, (e.g., adequate hospital stays for Medicare SNF coverage) and avoidance of costly treatments that would push beyond payment. A referral with Medicare and a second payer source, such as Medicare or Medigap insurance was considered a valuable potential patient. One nursing home administrator noted “... you have to make a decision pretty quickly, because if you don’t, you miss out. And so sometimes it’s, if they have Medicare and Medicaid, you’re like: ‘Oh, that’s a great referral.’ And, they’re a certain age, a lot of times you’re saying, ‘Okay, let’s just go ahead and say yes’ without maybe even having the whole picture.”

Facility characteristics and staffing patterns also served as boundaries for acceptance of referrals. The admissions coordinators described physical plant issues that limited either their ability to accept patients or their attractiveness to the resident. For example, the design of their toilets dictated that one facility could not accept anyone over a set weight without having a

private room and additional equipment. HCPs from both SNFs spoke of the difficulties of older physical plants in their ability to attract Baby Boomers who wanted to maintain their active lifestyles. Lack of internet access and patient rooms set along long hallways were both described as dissatisfiers for this population. Staffing patterns also limited patient populations. For example, without respiratory therapists acceptance of residents with tracheostomies was not optimal.

Medical stability, a standard criteria for hospital discharge, was a concern for both of these nursing homes. Both saw SNF patients as more acutely ill than in years past and had concerns that accepted patients had needs beyond the facilities' capabilities. Admissions coordinators from these facilities did not consistently visit patients in the hospital before acceptance. Therefore, they were accepting the patients "blind" to their true clinical picture. "The people that come in are sicker... it's not just the typical "joint camper" [a hip or knee replacement] that is here, so we get a lot of congestive heart failure people and chronic obstructive pulmonary disease patients and [my colleague] likes to say when they come in they've got one foot on a banana peel...They have managed at home, just barely and something has happened to take them to the hospital and they're still on that banana peel when they get here." Another administrator suggested, "Hospitals are trying to send residents to our communities when they are still too acute to be in our facilities. We are not prepared to take care of them when they come when they're not stable. I just feel like a lot of times we're getting residents that when they get here they're in worse conditions than we're aware of."

Coordination of the workload across transitions was handled differently in each of the SNFs. In one, the admissions coordinator was a social worker. Here coordination with the direct care management team was consistent and ongoing. The SNF nursing unit leader was involved in evaluating residents for acceptance. Unit staff, who completed admissions once the resident

arrived, would take nurse-to-nurse report over the phone before the transfer occurred. In the other SNF, the admissions coordinators were nurses. Here, they were much more independent in evaluating and accepting residents. Their role continued through medication procurement and reconciliation and development of an initial care plan. In this facility, per diem admissions nurses came in solely for the purpose of completing the admission assessments and settling the patients. After, they would hand off care to the direct care staff.

Both SNF admissions coordinators spoke of the importance of first impression to the success of the overall stay. "It's that first impression when they get here that is either going to make you or break you. You know? I mean if you can... they walk in the door and you can make sure that they're greeted and make sure that they're taken up to their room and shown everything that they need. Make sure that they're comfortable. Make sure they have those pain medications and everything on board right away. That feeling can change pretty quickly, but, you know, if you're not ready for them and the room isn't ready and it can be a much worse situation." Another admission coordinator said, "Our goal is to have (the) best outcome. That first day is key to managing that. That, if we get an overload of admissions and the staff is stretched too thin, then, you get a bad first impression. And if Mom and Dad have sat there for 45 minutes and nobody is coming to actually start that admission process, then by the time [the admission nurses get here], they're pretty annoyed. And, when you start off on a bad note, then, they're going to pick us apart all along the way."

Once admitted, management of the patient's clinical care and discharge planning was coordinated through a combination of structured multidisciplinary meetings. Regulations require care planning meetings between SNF multidisciplinary staff, patients, and families. One facility aimed to have the first occur within two days to two weeks. The other SNF allowed more time to pass before the first care planning meeting. These meetings were seen as an

opportunity to identify and resolve concerns before they became too big to deal with. They were also used to ensure that discharge planning was considered early in the admission. For SNF management, care planning meetings occurred one day per week, with leaders from each of the departments in attendance. Patients and families attended 20-minute long meetings in which patients and families described concerns and asked questions and each of the departments discussed progress and concerns.

Discharges occurred in response to regulatory requirement, as well. Two regulatory requirements were described as the reason for SNF discharge: a Medicare copay beginning on day 21 and daily skills needs. “Day 21 there’s that co-pay and a lot of our Medicare don’t have a secondary (payer) and so regardless of if maybe they’re ready, they’re leaving.” Lack of a “daily skills need” was also referred to as the reason for discharge. Progress towards the rehabilitation goals established within regulatory guidelines OR a “plateauing” in the progress were reasons for Medicare to discontinue payment for the admission based on daily skills need. Within 48 hours of this determination, discharge occurred.

Within the study, hospital readmissions occurred from both SNFs. However, discharge to home was observed from one. In this facility, formal discharge planning meetings occurred with the clinical care and therapy leadership, a social worker (who supported discharges), and the MDS (Minimum Data Set) staff. Each week, during this meeting, staff reviewed progress toward therapy goals and the potential for discharge in the coming week. They also discussed concerns seen in clinical care. Although direct care therapists documented progress toward goals in the chart, it was this meeting that prompted discharge planning to begin. In the 48 hours prior to discharge, requested appeals were filed and all planning and coordination with the principal, family and home health was completed.

Contexts were quite different between hospitals and SNFs. Beginning with patient evaluation and acceptance in to the SNF, financial considerations were prominent including adequate payment for care needs and management of care requirements within staffing levels. SNF acceptance and admission processes included much fragmentation of responsibilities by role. For example, a different staff member might do each of these necessary steps: approve the referral, take report from the hospital nursing staff, greet the patient and complete the admission paperwork. Likewise, admission, care planning and discharge planning were coordinated through management staff while day-to-day care was handled by direct care HCPs. These unique contexts had implications for the principal and family caregiver experience within the SNF.

Movement between facilities. Each facility saw the admission and discharge processes in terms of boundaries. At admission, accepting HCPs took over responsibility for care of the patients. Access to information was at its peak during the admission process. If the HCPs chose to reach out for additional information from others, the information was most likely to be shared at this point. There was no evidence within the cases of HCPs reaching beyond system boundaries for access to information. For example, upon assignment of a new physician, there was no documentation of information requested from former physicians other than within the hospital medical records. Likewise, at discharge, there was a window of opportunity for sharing information with the newly accepting facility. This window did not include the option for gaining feedback from the accepting facility. A hospital HCP shared, “The problem is that we don’t get any follow up with patients after they leave to tell us how we did.”

Although medical providers, such as physicians, physician’s assistants, or advanced practice registered nurses, may have moved across boundaries, roles and mechanisms for communicating changed. Documentation within the medical record was the dominant form of

communication within these facilities. As such, with movement outside of the facility, communication changed. Within the hospitals, whether using a solely electronic or a combination of electronic and paper records, neither continued to the SNF. Therefore, access to past records, including the current admission, diminished. Sharing of SNF documentation with medical office documentation was limited to short paper summaries transported with the patient at the time of office visits.

The information available, the decisions made based on that information, and the outcomes of care were communicated across boundaries at transition. Discharge summaries, histories and physicals, and consult reports are all examples of clinical documents reporting the thinking of the sending HCPs. At the point of discharge, consideration of the patient's situation and what care was needed began anew among the HCPs accepting the patient. No evidence of collaboration in clinical decision making across facility boundaries was described within the facility findings nor seen within the study.

In summary, hospitals and SNFs operated as separate organizational entities, with few connections between them. The connections that did exist took place within a brief window of opportunity for information sharing. The information actually used tended to be information about principals' eligibility for care within the facility. Clinical information was shared, but was considered in the context of assessment and planning within the accepting facility. Medical providers sometimes provided continuity, but their roles and avenues for communication were different in the hospital and the SNF.

Life transitions. Facility-level contexts provided the processes and HCP approaches to care transitions, thus, framing the principal and family caregiver care transitions. However, principals and families arrived with additional context – the principal’s life transition.

These life transitions were the result of aging with advanced (and advancing) chronic illnesses. Life transitions were described in terms of narrowing possibilities, experienced as fewer safe and attainable options in many areas of life for the principal. As they experienced these narrowing possibilities, the principals fought to maintain their identity and to identify acceptable boundaries within their new reality.

While care transition processes were central to the facilities and HCPs, the life transition was primary for the principals and their families. They worked with HCPs to resolve acute clinical issues and adjust regimens for the chronic conditions at care transition. However, the principals and families typically considered the ongoing life transition to be more personally threatening than the impending care transition.

In this section, I will describe the life transitions seen within the cases and share the common struggles shared by all principals. These common struggles were narrowing possibilities, maintaining identity, and identifying acceptable boundaries.

Narrowing possibilities. Principals consistently described their own transition into a phase of life with narrowing possibilities. As the principals experienced the effects of aging and advanced chronic illness, the number of options available to them were becoming fewer, were narrowing. They experienced narrowing in their ability to be independent in activities, both sources of joy and parts of their identity. For example, they were no longer able to support their families through gardening, cooking, and childcare, among others. Likewise, the principals’ narrowing possibilities made hobbies that had been a source of joy difficult to manage. At times,

the principal simply gave up the activity. At others, family members acted to support them. Principals also experienced narrowing possibilities in their abilities to care for themselves and their homes. Some managed through by modifying their homes or considered hiring out jobs. Others reached to family for help. As family and HCPs became aware of the increasing need for support, they began to consider the principal's safety more broadly.

Although each principal experienced narrowing possibilities uniquely, they all found that the options and opportunities available to them were decreasing. This change related to a number of factors: recognition that they could no longer perform roles or tasks that they had in the past; need for support in maintaining their home, medications, or other activities of daily living; and financial constraints. For some, the transition was experienced as slow and gradual. For others, recognition of change came suddenly. However, for each principal their experience of the hospitalization and subsequent SNF admission was flavored with recognition of life as they knew it changing.

For some the narrowing possibilities reflected their need for physical and/or cognitive support in many areas of life. For example, although Mary's family had been supporting her for years prior to the index hospital admission, Mary viewed their time together as 'visits.' In reality, her family supported her in taking care of her and her home as she no longer walked outside independently. They scheduled and drove her to all her appointments, shopping, and social events. Her family scheduled her medical visits, accompanied her, and managed her medications. A member of her family wrote out checks and tallied the checkbook, Mary still signed them. Although Mary lived alone in her home, her family visited multiple times each day. Mary's family managed routine tasks of home ownership such as yardwork and taking out the garbage. Mary's possibilities at hospital admission had narrowed such that she was no longer purely independent in any area of her life.

For other principals, the narrowing was limited to specific areas of life such as their ability to drive, to manage their medications, or to continue with activities that were precious to them. Two of the principals recognized narrowing only at the hospital admission. While both anticipated returning to 'normal' following their return home, only one principal still had hope of being independent at the conclusion of study participation. For the other, progression of congestive heart failure and sequela of its treatment contributed to advancing chronic renal failure and additional hospitalizations. From the beginning to the end of his study participation, this principal progressed from social visits with family to requiring an organized network of multiple family caregivers to support his return home.

Although narrowing possibilities was in some cases perceived as an acute event, evidence of narrowing possibilities was heard in principal and family caregiver retrospective accounts of life prior to admission and seen in longitudinal data collected throughout study participation. Their stories included letting go of treasured past-times because they were no longer able to enjoy them. One principal with failing vision described his love of reading books and dissatisfaction with alternatives. "If I can't read a book holding it, I guess I don't really crave it...it's important to me to be able to hold a book, go back and reread something if I've missed it..." Similarly, he noted that going to his grandchildren's activities was difficult. "I'd like to participate, get back on my feet so I can go, and oh, go to the band concerts, for example, or go to the swim meet. Those sorts of things, you know, and enjoy the grandkids." Another principal rather casually addressed narrowing possibilities with her acceptance of loss of a past-time: "I loved to work in the garden, but of course I can't work in there now." In contrast, the principal's family described the time and effort spent in gardening and its value to the family: "In the summer, she had, you know, a huge garden and flowers. And, she was outside. And..., she just couldn't do that anymore...When she gardened, you could count on, if the beans were picked

that you would have a half gallon bag and they would be ready. They would be cleaned, broken. They would be ready.”

Advancing chronic illness contributed to narrowing possibilities. Advancing chronic illness came with decreased strength and stamina. “We used to go to the fabric store and for groceries, everything on Thursdays, and it became a little bit more that Mom would just go to the fabric store and then, we would go to the grocery store. And, then, the fabric store, my mom would find what she needed and then, my brother would take her out and, then, I would wait while everything was measured. So, that part has been, you know, creeping up.”

Increasingly complicated medical regimens were beyond the ability of some principals and their families to manage. Here, narrowing possibilities included the need for HCPs coming into their home routinely. “[My family caregiver is] not trained to deal with **that** [sequela of treatment]. And,...,we could have visiting nurses come in and do all that, but, that’s not the same.” For another principal, his inpatient care manager in concert with the specialist leading his care suggested that the goal of treatment was to “keep him out of the hospital.” He was considered unsuitable for more advanced therapies because he was not able to understand his complex care regimens to their satisfaction. (John initial hospitalization, pg 48) For some, there were frequent interactions with their primary care practitioner and multiple specialists. One principal described visits with 3 specialists and a phone conference with his primary care practitioner in less than one week. The financial implications of advancing chronic illness also took its toll on the principals who were all living on fixed incomes. One family member described concerns about the principal’s financial future: “There is not the finances to pay for, and I had tried to apply for Medicaid, although she doesn’t own the house anymore. And, her expenses were mostly her medications. They would run a huge percentage, you know, 700 – 800 dollars a month...And we knew, between the three of us that, we are retired, we just could not afford, we

could for a while, but just could not afford that care on our own.” These implications of advanced chronic illness consumed resources and contributed to the narrowing of possibilities.

Before the initial care transition into the hospital, seeds for narrowing possibilities had already been sowed. Life choices, sometimes years past, lead to these dwindling financial resources. One principal had sold her home to one of her children with the promise that she would live there until her death. His impending financial hardship dictated the sale of the home that she had shared with her husband and family. Multiple hospital admissions coming with increasing frequency signaled reduced resiliency for stressors, such as a viral infection or a fall. For three principals there had been foreshadowing of a needed surgery or weakening immune system. Despite such foreshadowing, each of the initial admissions occurred through the emergency room. Limited social support networks supplied few resources in times of need. A principal, never married and without children, described HCPs’ responses to his desire to go home: “We want somebody to be around because you’re single.” He responded to their request, “If I lived with somebody I wouldn’t go through any of this shit.” One principal described friendships from years ago, long lost. His current relationships were limited to his wife and children’s families. “Before we were married, I had a friend that he and I would get together. I had a boat and we would go boating and we would just go out to dinner and so on, but that contact dropped when I got married. It has been primarily relatives.” Gradual increases in family support left few truly independent activities. For two principals, support was needed multiple times daily to enable their living at home. Each of these personal situations indicated an area of vulnerability as advancing chronic illness increasingly affected the principal.

Although narrowing possibilities were not instigated by the hospitalization, the hospitalization increased external focus on the principal’s vulnerabilities, adding energy to dynamics already in place. For example, the hospitalization caused unwanted evaluation of the

principal's questionable living arrangements. For the principal who considered him or herself safe and happy in their pre-hospital situation, this evaluation caused concern that for either short or long term, they would not be allowed to return home. "My strength is coming back and so, but my [caregiver] can't take care of me at home. She's not trained and doesn't feel comfortable trying to." In response to a question about his ability to go directly home, John responded: "I think I could get along. I mean people may not think I could cope, but I could cope. I've coped with as bad probably or worse." This principal transitioned to SNF care at hospital discharge at the urging of HCPs.

The hospitalization also prompted evaluation by families providing care to the principal. For families providing substantial care, this evaluation offered the opportunity to determine the load was not sustainable. "Someone is always over making sure that we put out my mom's medications for the next day and help her with her insulin. Two of my brothers..., they were in and out maybe 4 or 5 times a day." After admission into long term care, the daughter commented: "Actually probably spent more time before....This, this is more visiting and fun. Before, it was more, you know, doing the laundry, cleaning the house, helping with the shopping, paying the bills....So, it, to me, there is not that, oh my gosh, you know, not exhausting." For those who were not involved in care, it allowed families to determine that additional care was needed. "I'm concerned about her health and when she's at home if she's getting the care that she needs."

The hospitalization prompted the principals to evaluate what the rest of their lives would be like. Principals considered where they were in life compared to parents and siblings. They noticed at what age and in what situations their parents died. They noticed whether they were more like their father than their mother, anticipating that they would have similar longevity. "We lost my dad when he was 70 years old to a heart attack, and you know, that

worries me that we lost him and where am I fitting into this. My mom was 89, so she, you know, I have mostly my dad's genes apparently. This is worrisome." The principals also considered what current events meant for them. Would they return to life as before or would this cascade of events lead to dramatic changes? "I think of my grandmother taking care of a great uncle and the work that she put forth just to struggle to get him to his chair in the bedroom ... It was a matter of getting him up and he never got downstairs or anything, but, you know, his quality of life was not good...Hopefully I can get mine better than that" Another reflected: "I don't, I don't know whether I could go home or not. I don't know yet...I doubt it, but I don't know because I am 94 years old."

These principals, in the midst of life transitions, were dealing with narrowing possibilities that diminished their independence in important and beloved activities. They attempted to manage through the effects of advancing chronic illness including decreased strength and stamina, complicated medication and treatment regimens, frequent interactions with HCPs, and financial hardships. These attempts to manage through were hampered by dwindling financial resources, reduced resiliency for stressors, and limited social support networks. As their narrowing possibilities advanced and principals had few truly independent activities, two goals held the principal's attention: maintaining their identity and creating acceptable boundaries.

Maintaining identity. Despite their narrowing possibilities, each principal continued to view themselves as a unique and independent adult. The identities that they shared with the researcher and strived to maintain revolved around their roles throughout their adult lives. They were strong and independent. They were productive leaders in their family and community. In the context of their ongoing life transition, including narrowing possibilities, these identities

were threatened as the principals were less able to perform. As the principals dealt with the threat, they talked about who they were professionally and personally throughout their lives.

Each principal shared the hobbies that they enjoyed, their life's accomplishments and the relationships that made them unique throughout their adult lives. One principal, shared his successes during a long teaching career. He considered himself a pioneer in his field who made strides in teaching both for young women and for those with lifestyles that hampered their learning. Another spoke of family events in her home: "I make real good fried chicken. I got 17 when they all get together at the house and I fix most of the meal." Tradition, even up to the index hospital admission, brought family to her home for Sunday dinner each week. She also shared experiences as a seamstress. "You know, I like to sew and I made a dress and I won a prize. And, it was in the local paper...I mostly sew dresses for my great-grandchildren. I sew all kinds of dresses, its beautiful dresses...One year, I made 35 aprons. I made them for everybody in the family." One principal shared summers with his family on a lake. Another principal shared that she enjoyed going to the casino. She shared stories of her greatest wins and her plans for going back once she was able. "...I only take \$20 now. You know, sometimes I win and sometimes I lose, you know. I'd go, that's one place I don't mind going by myself."

During their SNF stays, the principals looked for activities and relationships to engage them and confirm their identities, as well. John spoke of being bored in the SNF and what he would like to do in his spare time. He described the activities that would make his life more enjoyable. "It would be individual things like working on my fishing equipment or having access to my fishing books, which I have a whole collection. Or, tying a bunch of fishing flies or making a bunch of fishing lures." Eva struggled to keep up with televised sports events. Her glasses were damaged in her fall, making it difficult to read activity schedules. In addition, she found moving independently in her wheelchair challenging. In her stay at the SNF, Mary wished to maintain

her home activities. She asked for her sewing machine to be delivered. Her family continued to visit daily providing normalcy, as well. Lou played cards and completed puzzle games when his family was not visiting or talking with him on the phone. These SNF activities did not parallel the many precious roles and hobbies that the principals performed in their homes, making the time in the SNF difficult.

The principals also described their activities and relationships within the context of narrowing possibilities as their participation within the study drew to a close. John shared: "Not a total waste of my life. I was able to get my godchild some money, another five grand to go to nursing school." Through substantial effort with his family and HCPs, John was looking forward to returning to his own home at the close of study participation. Mary, no longer able to manage the sewing machine independently, had picked up other activities that reinforced her identity. She attended church services whenever they were available. She had re-established her home routine maintaining engagement in new-found activities throughout the day. She described the things that she liked doing in long term care, "like going to mass is one of them and they have, like, ceramics. And, I painted an angel and Blessed Virgin and the turtle over there." Once Eva returned home, she engaged with her family and neighbors again, watching "the game" at a neighbor's home and enjoying time with her grandchild. She looked forward to returning to the casinos even if she was no longer able to go independently. Lou strived for as much independence as possible, allowing his family to go on with their lives, even if he could not participate. He described his family's approach to being supportive of parents as they neared the end of their lives while maintaining other commitments, as well. He attempted to give his wife and children permission to do the same, "[Family member] has things that she has to do and she feels sorry that she can't do like what her mother did and I said, 'No, you have to do

what you have to do. You can't come and sit **here**. Your health will deteriorate too if you don't get done the things you need to at home...Life still goes on even though I'm not there."

Each of these principals experienced the life transition as a threat to their identity. They looked for opportunities in the SNF to do the things that projected and reinforced their identities and once in their home environment, returned to maintaining the roles that were precious to them to their fullest abilities.

Identifying acceptable boundaries. As narrowing possibilities became constrictive and maintaining their identities an effort, the principals also created boundaries of what was acceptable to them. For example, as she accepted a narrowed, but adequately supportive environment, one principal suggested, "This is sad." Other principals set boundaries that eliminated such supportive facilities: "I don't care if I have to crawl up the front steps of my house, I'm not going to a nursing home. If you're going to send me to a nursing home, just take me down 30th street, throw me in front of a metro bus." For other principals, the established boundaries were not about where they lived, but how they lived. One principal described his angst with increasing needs in terms of its effect on his family: "because that will, that just, you know, would mess up our home life completely."

In evaluating boundaries, the principals generated new options that were more acceptable than those directly offered by family and HCPs. The principals looked for alternative living arrangements such as living with a family member. One principal, following his first hospital readmission, worked with the hospital social worker to plan for discharge to a family member's home. Prior to his final discharge, he worked with multiple family caregivers and HCPs to ensure adequate support for him in his own home. Another principal requested to move in with a family caregiver, but the request was denied. The family caregiver shared that she felt

unable to provide for the principal's many needs, citing that the family caregiver was older, as well. The principals re-evaluated treatment options, suggesting that treatments currently in use were not needed long term. "I think I can get off of oxygen, because I don't want to get oxygen dependent."

In addition, the principals considered updating or changing their homes. Some came to the conclusion, that they would not make changes. Others identified repairs or improvements as critical to their success at home. "They'll probably have to go out and do an assessment of my house....You know, to see if I need to have any, you know, grab bars or that put in." Another reconsidered his home, surveying all of the changes that had been made to support his living there: "Everything is set up at home. I have the walkway up the ramp to the front of the house so I don't have to step up steps. The house is flat. I have the riser on the toilet. I have the tub bench in the tub, which was set up in the past. My wife and daughter got me a new chair last summer that has the lift if I need it..." These changes often required the support of family members or financial resources such as Medicaid or local charities, but offered the potential for slowing the narrowing process.

Conflict resulted when principals' identities or acceptable boundaries were threatened. This conflict was between principals and family caregivers when their understandings of the principal's situation differed. In Eva's description of her home life before the hospitalization, she shares, "We have no problem. Everything goes fine. We get along good." However, her family caregiver shares, "I didn't that this she [Eva] was getting out of the house enough. [Another family member] does live there, [she], herself has a lot of health problems,....I don't feel that she is giving my mom the care she needs." This family caregiver strongly encouraged Eva to move into her home where she could have additional support. Eva refused, leaving her family caregiver unsure of how to ensure Eva's safety. Conflict also resulted when HCPs disagreed with

principal boundaries. In most of his admissions, HCPs and family involved in John's care determined that he required SNF care following discharge from the hospital. He disagreed. Resolution of these conflicts required modification of care transition plans to accommodate the life transition or adjustment of the principals' embodiment of their identities and boundaries.

These life transitions dominated the principal's concern. Narrowing possibilities threatened their future, their identity, and their ability to live within acceptable boundaries. While the clinical reason for the hospitalization was an obstacle to returning to "normal," the hospitalization and impending care transition were minor issues in comparison to the life transitions.

Care transitions. Principals' life transitions served as the context for the index hospitalization and the care transitions that followed. In contrast to the life transitions, care transitions were time-bounded processes involving specific settings and HCPs. Here, we focus on facility transitions, a subset of care transitions including the planning, coordination and movement of patients from one facility to another or to home. HCP and principal and family caregiver experiences of care transitions between facilities were distinct. HCP findings included: number, rationale and timing; effect on continuity; and logistics. Principals and family caregivers spoke in terms of distinct occurrences within the care transition process. For example, determining a list of facilities at the next level of care was challenging for some principals. The care transition process as experienced by principals and family care givers is also included.

HCP findings related to care transitions.

Number, rationale and timing. Within the cases, there were 24 facility care transitions. Each of the four cases had three facility care transitions in common: an initial care transition from home to hospital; a second from hospital to SNF; and a third from SNF to home. In three of

the four cases, the principal returned to either their or a family member's home. However, in one case, this care transition was to a nursing home for long term care.

Three of the four principals experienced unplanned care transitions during these cases. These unplanned care transitions lead to emergency room visits (2) and emergency room visits requiring hospital admission (6). Two principals, Mary and Lou, completed their SNF stays without hospital readmissions. However, on the day of SNF discharge, Lou was seen in the emergency room of his index hospital. Thirty days later, he was admitted to his index hospital through the emergency room. He died during this hospital admission. Eva experienced two hospital readmissions and one emergency room visit without hospital admission during her case all within her index hospital. Each time she returned to the same room within the same SNF. John was readmitted to his index hospital within two weeks of his initial hospital discharge. In route to this hospital by ambulance, he was determined unstable and sent to the nearest hospital. After stabilizing him, he was transitioned to his index hospital. Following discharge to a family member's home, he was readmitted to the same hospital. His family selected a second SNF where he transitioned. After three days, he was admitted to ICU at a third hospital. From there, he transitioned to a long term acute care hospital. At the end of study participation, he anticipated returning to his own home with much family support. See Figure 4.3.

Complex clinical care was needed at the time of each of these hospital readmissions, exceeding the abilities of the transferring level of care. Two of the hospital readmissions were directly from SNF to the ICU. A third readmission included transfer to ICU after admission to a medical unit. Two principals experienced unplanned invasive procedures during readmissions to resolve clinical issues. At the time of care transitions, the principals were experiencing clinical events such as low blood pressure, hypoxia, bradycardia, symptoms of stroke, abnormal bleeding, and unexplained fevers. In each of the situations management required hospital care.

Unplanned care transitions largely occurred in close temporal proximity to the initial discharge. All but one readmission occurred within 30 days of the initial hospital discharge. The last occurred within 90 days. For the two principals with multiple readmissions, the initial readmissions occurred within two weeks of the initial hospital discharge.

Logistics. In planning for care transitions, a number of logistics, or details necessary to facilitate coordination in the transition, were managed. These logistics were coordinated to accommodate the needs of each facility, the principal, and the family. Within these 24 care transitions, clinical need, regulatory requirements and practical necessity for each of the facilities, principal and family were considered. Although the needs of multiple players were considered, details were negotiated between HCPs responsible for the transition for each of the facilities. Dominant among the logistics were the timing of movement and the details of transportation.

In moving to higher levels of care, such as SNF to hospital, timing was quick and without debate. However, timing of movement to lower levels of care, such as from hospital to SNF, required negotiation. For two care transitions, principals were held in the hospital over a weekend to ensure that a preferred SNF bed was available. In other cases, principal transitions from hospital to SNF were carried out rapidly. In one of John's readmissions, his identification of the "list" of preferred SNFs to actual transition occurred in less than 24 hours. For one principal who experienced new symptoms the morning of transition, timing of the transition was moved later in the day. However, an end point was placed on the available time to ensure that the SNF had adequate staff to manage the admission process.

There were multiple options for transport within the care transitions. However, in practice, patterns existed in transportation used by level of care. Although private vehicle was

an option for many types of transitions, only transfers to and from home did. From hospital to SNF, transportation options ranged from private car to ambulance. However, since this service was at the expense of the principal, hospital HCPs worked with SNF providers to accommodate the movement with as little cost as possible. In these cases, principals were transferred by medivan, a private transport service that is less expensive than an ambulance, or SNF transport services. From SNF to emergency room, each principal was transported by ambulance.

These logistics had consequences for the care transition. For example, transportation choices held implications for the number and types of workers encountered by the principal. For principals transitioned from hospital to SNF by nursing home transport, these same staff members were also involved in trips from the SNF to office visits. However, for principals transported by medivan, there were not typically additional encounters with these staff. Further, in two ambulance transports from SNF to hospital, the principal was rerouted to the closest hospital due to medical condition. On one occasion, the principal was stabilized and returned to the index hospital. On the other, the principal was admitted to ICU at the receiving hospital.

Effect on continuity: relationships and clinical care. As principals moved through their multiple care transitions, they encountered an enormous number of HCPs, who worked with the principals in a variety of ways. Most were short term facility-based encounters while others had varying degrees of continuity across settings. Regardless of their duration, principal and family relationships with HCPs changed with each care transition. For example, each visit to an emergency room brought introduction of new medical providers. Tables 4.3 – 4.6 show the types of HCPs involved with the principal as he or she moved through multiple care transitions. The emergency room-based physicians within these cases tended to be new to each principal. With the exception of Mary, whose family called her primary care physician prior to taking her

to the emergency room, all of the principals were seen by new primary care practitioners and/or consulting specialist(s) in or soon after the emergency room. These primary care practitioners and specialists were introduced because the principal did not have a relationship with the needed specialist, or the physician with an established relationship was not on call or not affiliated with the admitting hospital. John's experience was the most extreme example. He was admitted initially within a hospital system that was known to him. His first two readmissions were within the same hospital, but with different primary medical teams. On the first admission, a medical specialty and a surgical specialty team each took lead. On the second, a second specialty surgical team was lead with family medicine managing the discharge. On the third, family medicine managed his care. His fourth admission was to a different facility where he was assigned a completely different group of medical providers.

From hospital to SNF, relationships changed once again. Specialists that had been seeing the principal in the hospital on a daily basis shifted to seeing them in office visits at intervals of weekly to monthly. In these four cases, the primary care practitioner relationship also changed. In only one of the cases, the primary care practitioner of record within the hospital visited the principal personally on a weekly basis within the SNF. In all others, either a nurse practitioner was contracted to provide coverage during the SNF stay, a practice representative visited for all patients within the facility, or the facility medical director took over care responsibility. In all situations, although there may have been collaboration between the covering and the established primary care practitioner, the principals did not experience the connection.

Each care transition required establishing new relationships with facility-based HCPs, as well. Facility-based HCPs, such as individual nurses and therapists, were available within only one particular facility. Therefore, with each care transition, new direct care HCPs worked with the principal and family. In spite of returning to the same hospital on readmission, principals

were admitted to different units (e.g., a medical floor on one admission, a surgical one another). In these cases, the principal and family met new facility-based HCPs, as well.

Furthermore, for each of the principals, hospital admission and readmission occurred in processes that also introduced additional groups of HCPs. Once again, John is the extreme example. In his initial hospitalization, the decision to admit occurred during a clinic visit. He was transferred to the emergency room for evaluation and care and then, to a nursing unit. Within the hours between his clinic visit and admission, John experienced three different groups of HCPs. At each readmission, the pattern was similar, steps between facilities introduced separate groups of HCPs. For most readmissions, these steps included SNF to emergency medical services to emergency room to hospital unit. Over the course of his case, John was treated in six different facilities (three hospitals, two SNFs, and a long term acute care hospital). Between and within these facilities, he encountered multiple HCP groups: clinic HCPs, emergency medical technicians, emergency room and nursing unit staff. During her case, Eva was seen within one hospital and one SNF. However, each of her three hospital admissions was to different nursing units.

In addition to care transition for an increased level of care, care transitions could also be triggered when the principal was considered to have met level of care requirements. However, when the level of care requirements were met, clinical needs were not consistently resolved. For example, hospital level of care requirements were consistently described as 'medical stability.' However, principals were considered medically stable with multiple ongoing clinical needs. Likewise, SNF level of care needs were resolved when therapy goals were met. Additional ongoing clinical needs were seen in each of the principals. Therefore, continuity of clinical care was affected by care transitions. Management of the clinical needs identified within the hospital admission persisted up to the time of hospital discharge and was continued on arrival in the

SNF. These clinical needs included management of ongoing chronic conditions such as hypertension, diabetes mellitus, and anxiety as well as acute problems such as nausea and vomiting and medication management. At SNF discharge, principals were still working to manage blood pressure, oxygen requirements, and continued on antibiotics.

Management of clinical needs and symptoms across transitions proved difficult at times. For one principal, adjusting medication dosage through frequent laboratory testing continued through the initial hospitalization and SNF admission. At readmission, the medication was discontinued without achieving a stable dose due to the implications of multiple chronic conditions on medication metabolism. For another principal whose transition to the SNF had been cancelled earlier due to a hospital acquired infection, in the hours before planned hospital discharge and SNF admission, new signs and symptoms were medically managed. The principal was transitioned as planned. The underlying problem, an acute illness unrelated to her chronic conditions or her admission diagnosis, was treated by advancing medication doses up to the time of her first readmission.

All principals experienced management of ongoing clinical issues across care transitions. However, not all of these issues resulted in additional care transitions. For principals experiencing clinical issues that could be managed within the resources of the facility, readmission was not considered. Within this study, hypertension and glucose management were examples of problems effectively managed within the SNF. In addition, infections identified early were managed with oral antibiotics within the SNF. However, acute situations requiring ongoing enhanced medical or nursing presence, quick turnaround times for laboratory studies or medication changes or situations in which the principal or family felt additional resources were needed prompted visits to the emergency room.

Principal and family experiences of care transition processes. Within the Facility-level context section, I described the norms within the participating hospitals and SNFs as described by HCP experts. In this section, I chronologically consider care transitions as seen within the cases. I also share the principal and family caregiver perspectives of care transitions.

Each of the care transitions began with a decision to move. These decisions to move were not inclusive of planning, but rather acknowledgement that the current level of care was no longer acceptable. This was true whether the move was from a higher level of care to lower or the reverse. For the principal at home, this was the decision to go to the emergency room. In each of these cases, the decision to move from home to the emergency room came as a joint decision with the principal, family and, on some occasions, HCPs, as well. Principals spoke of their family's encouragement to go to the emergency room: "My wife and daughter both said, you probably should go to the hospital." And, families described their decisions when the principal was not able to independently decide, "when my sister got over, she said in a while she noticed... [the principal] was [making gasping sounds]...so, the doctor's office said to go to the emergency room."

Within the hospital or SNF, decision to discharge from the higher level of care to the lower or in the SNF to send the principal to the emergency room preceded the care transitions. In each case, the sending facility reached out to the principal and/or the family to confirm their support of the decision. In John's first readmission, he requested transition back to the hospital after a new onset of symptoms. Although nursing staff did not agree with the decision, they complied. The triage nurse covering at the time, described clinical options for caring for him in the context of the new symptoms, but described John as insistent that he return to the hospital and the medical director as supportive. This description matches his accounting of the situation, as well. In transition from the SNF to home, discussions regarding timing and planning also

engaged the principal and family, if only in the details such as time of day to be picked up and which medications would be continued at home. In working with Eva and her family caregiver at discharge, the nurse practitioner considered the discharge plan line by line with the principal. On one occasion, the decision to discharge was contested. However, once it was determined that insurance would no longer pay, the principal and family complied with the discharge plan.

After the decision to make a care transition was reached, the decision was made regarding where to move. For many of the principals, selection of a hospital was not verbalized as a considered choice. Rather, their family drove to the closest or their physician referred to an admitting facility. For others, a long history made one facility the most obvious choice. However, at times the decision regarding where to move created conflict. In two transitions from SNF to emergency room, a principal was taken to the nearest hospital by emergency medical services due to a medical emergency. In John's transitions from hospital, he contested the need for SNF care in all but one occasion.

In selecting the SNF, principals and families considered location, continued care within a healthcare system, and personal references. Principals wanted to be near family to make visitation convenient. For example, John noted that his family would be able to visit him on their way home from work. Lou talked of his family's ability to visit during the day and still be available to pick grandchildren up from school. Mary transitioned into a SNF where another family member was also a resident. The principals and families also spoke of others' experiences within local nursing homes. These stories, whether from family, friend or neighbor, served as references for the nursing homes. At times, the experiences were years past, but still served as a connection to the chosen facility. None of the families chose to visit the nursing homes prior to making the decision to transition there. One principal asked that his family visit the nursing homes prior to making a decision. However, no evidence of an actual visit was found.

As the decision to transition to either a higher or lower level of care was made and the site was selected, information about the principal and their current situation was shared. During facility-to-facility transitions information was shared between HCPs prior to the move through formal mechanisms including written and verbal report. These reports were framed by the information that the sending facility had considered important during their admission. For example, in an admission focused on an acute event, medical histories might have been abbreviated to minimize distraction from that which was considered relevant to current episode of care. This abbreviation would force the same focus at the next transition because those HCPs sharing information would have only the abbreviated version.

The movement of information and the movement of the principal often overlapped. When the care transition was between facilities, the sending facility often sent information ahead, such as admission orders and a discharge summary. Additional information could be sent with the principal, as well. However, in each facility, even when information was provided by the sending facility, the principals and families gave their own information to the HCPs. The source of information was noted in the history and physical and consults by each of the specialists within the medical record. When the principal was transferred from a SNF to the emergency room, report from the sending facility and emergency medical services was noted. Otherwise, the principal and family were the only noted data source.

Once the principal had arrived and information was received, the facility or home-based HCP admitted the principal and provided needed care. As a part of this process, HCPs and administrative workers within the facilities addressed a combination of clinical, payment and legal questions to the principal and their family. In the emergency room, the process was relatively quick with clinical questions taking clear priority. However, in the nursing home, some principals and / or families stopped in the business office at arrival to complete administrative

paperwork. Although planned for a short term stay, each principal was asked a series of questions aligned with nursing home regulatory requirements. This admission process was noted to take up to 4 hours.

As the discharge and admission processes were completed, principals and families began to learn the new facility. Misalignments between expectation and reality became clear. Principals and family caregivers described their reactions to the SNF. As an example, John described arriving for the first time, “You know nothing about what’s going on at one of these places...I didn’t have no idea of even what it looked like. No idea what the rooms looked like, no idea what the food looked like. I mean I had no concept. I mean everything I did I took on word of mouth and go ahead and sign for it. I needed somewhere to go...I got dropped off at the front door here, I said, ‘I’m home. What are we going to do?’ ... I think you just got to come and see where you’re going to be.” At this first meeting, they were also aware of differences between reality and their expectations. These specifically related to the amount of therapy they received, activities, the availability of medical care, and the differences between the hospital and nursing home approaches to nursing care.

Within two cases, principals and / or families commented on the SNF facility physical characteristics. The daughter of one principal noted that the SNF lacked expected features of the transferring hospital. Several days after the admission, she offered her reaction to the SNF: “The staff is great. I think it’s a little dreary over here, you know, they could remodel and make it more cheerful.” The principal who requested that his family visit the facility before transition commented on his findings and his feelings related to the situation when he arrived: “I thought it was nice...it wasn’t spectacular...”

Three of the four principals and/or families commented on the clinical care within the SNFs. Two families noted that their principal was not being seen by physicians within the SNF. Rather, advanced practice registered nurses were providing medical care. The family caregivers voiced concern about the difference between hospital and SNF. "My biggest concern is doctors don't come over here. I do think [the] physician's assistant, she's very knowledgeable, but my concerns of if something did come back up, if her white cell count came up, how would we know? Or if she's getting sicker, because from my understanding, they're treating the pneumonia over here. That was my biggest concern. ... There's no doctors that come around." A principal also commented: "I don't know why they don't want to call the doctor, whether they think that, you know, what they're saying is the best and you know, my physician's assistant, I really like her. She's really nice, but I guess I just feel more comfortable having a doctor see me." Another principal, without the benefit of an accessible advanced practice registered nurse, noted the lack of access to medical care. "They weren't equipped to work on me with [those symptoms]." He described this further as the lack of physician, laboratory, and pharmacy needed on site.

Principals and families also voiced concern regarding nursing staff. One voiced in terms of knowing who to talk with regarding problems. "It's very hard when you come in to pick out who is who: who does what: what is going on." A principal was concerned that the nursing staff did not have adequate knowledge of his condition. "I don't think some of them have a clue as to what operation took place and what was done to people. I mean I may have said something to somebody and they understand that oh so and so has had a stroke or so and so has had a heart attack, but I don't think they're fully aware of all that's involved."

Within all of the cases, there was concern about the amount of time spent waiting at the SNF. Although there were scheduled activities at each of the SNFs, lack of communicated

therapy schedules prompted the principals to wait close by their rooms until daily therapy was completed. As their health improved, each of the principals experienced this waiting differently. John described boredom: “bored....bored...bored...I don’t see where anybody could have any hobbies here. I suppose you could, but I sure don’t see any.” “There was actually no activities to do. They didn’t have a library even to get some books out of. I mean ... they had nice TVs..., but you can only watch TV so much.” Mary experienced anxiety in the late afternoon and evening. Her family caregiver described Mary’s routine at home: “...she was busy from the time she got up until she got ready for bed. After, you know, when she would eat, she did her hand sewing, she watched something on television, chit chatted on the phone, just until she got ready for bed. And now it is completely different. Her routine is kind of waiting. You just kind of wait for physical therapy, you wait for occupational therapy, you wait for this, and I know for myself I, I, that's very hard not to have your day doing what you want to be doing.” After transitioning to long term care, Mary no longer had to wait for therapy. She became quite involved and self-directed in activities. Her anxiety quickly resolved. Eva was not comfortable moving herself about in the wheelchair. “The worst part is I can’t get out of this room very much...because I have to have somebody wheel me. It’s not very easy to wheel on this floor.” Her daughter described, “[They need] more activities where they get them involved....Because I feel like my mom goes to breakfast, stays in her room, goes to lunch.” Lou was the only principal who found positive ways to manage his waiting. He managed his therapy schedule, refusing to take all of his therapy in the mornings. In his view, this made his afternoons “too long.” He had cards and puzzle books that he enjoyed between therapy and visits with his family.

Principal and family caregiver perspective of care transitions. Principals and family caregivers rarely voiced concern or enthusiasm about the care transition process. For the majority of the care transitions, the principals viewed the move from hospital to SNF as rather

unimportant. “If you want to figure up the odds of something happening to me here [the hospital] compared to the odds of something happening to me there [the SNF], they’re no more severe for me there than they are here, so it makes no difference.” Another principal suggested, “I don’t have a problem with going to the skilled facility, because I just figure, you know, I don’t know how much therapy, but I’m sure they’ll probably do as much therapy as I did here and I get at least 3 hours of therapy here between OT and PT.”

There were two situations when principals and families became engaged with care transitions: when the transition was to home and when they found the option to be outside acceptable boundaries. For principals who were focused on going home the transition was embraced even if there were HCP and family concerns about the plan. For example, one principal from the first interview made clear that a home inspection would be needed prior to her return. She reiterated this expectation within two weeks of going home. She anticipated that the home would need added railings and repairs to steps. Her SNF initial therapy documentation concurred. However, when she was made aware that she would no longer meet level of care requirements and would be discharged in just a few days, the idea was dropped. She and the facility planned for the discharge without the evaluation or repairs. When asked about the change in plans, she commented, “Well, yeah, I don’t know if I’m going to or not. The backyard, the back door is just one step and I think I can get, use my right leg and get up that.” This principal went item by item through her prescriptions and treatment plans identifying those that she would continue and those that she would not upon returning home. In contrast, in planning for the initial SNF transition, she made the decision based on location and health system affiliation alone.

Principals and family caregivers also became engaged in transitions that they found unacceptable. When a principal and their family felt clinically unsafe in the transition or the

transition placed the principal in a situation that they considered outside acceptable boundaries, principals and family caregivers became intensely involved. For example, when Lou's family learned that he would be discharged from the SNF before they considered him ready, the family stepped in. They filed an appeal and when they lost the appeal, they worked directly with the nursing home HCPs to ensure the best available support at home. In all previous care transitions, Lou managed the process with HCPs independently.

At the point of hospital readmission, all principals and families understood the differences in level of care. Each readmission was acceptable to the family caregivers and to the principals. In fact, these principals and families were largely positive about readmissions. They did not view the return as a system failure. Rather, once they understood the level of care differences, when there were clinical changes, principals and family caregivers felt a need for additional support. For example, they looked for additional medical presence and quicker turn around on pharmacy and laboratory. John described the decision to return to the hospital for his first readmission: "That decision was made by me."

Care transitions, then, were complicated, tactically-focused HCP processes to ensure safety in movement between facilities. Best practice and regulatory requirements guided HCPs' actions with focus on norms within the clinical population. Management of logistics ensured that needed clinical information was shared and the principal's move was flawless. However, for the principal and family, these moves remained secondary to the ongoing life transition. It was in the dynamic interactions that complexity was clearly seen. In this context, the life transition and the care transition had the potential to connect.

Dynamic Interactions. The principals, family caregivers, and HCPs each came to care transitions with different issues and concerns. Principals and family caregivers were focused on

their ongoing life transitions with specific concerns regarding the clinical issues that prompted their emergency room visit. HCPs were focused on providing clinical care within the episode and level of care. To meet the principal's needs, each player needed the help of the others. Dynamic interaction between the principals, family caregivers, and HCPs connected life transitions to the care transitions.

In description of the dynamic interactions, I will consider the information available to and the focus of each of the agents (principal, family caregivers, and HCPs). Patterns in dynamic interaction, including familial approaches to principal support and principals, families, and HCPs working together will be described.

Use of available information. Dynamic interaction between principals, family caregivers, and HCPs was grounded on each player's knowledge and understanding related to the care and life transitions. Gaps in information related to the care transitions have been described – principals and family caregivers did not know of differences between hospital and SNF levels of care. HCPs also lacked knowledge of other levels of care. In addition, knowledge and understanding of the principal's clinical situation and support needs also varied across cases and individuals within them.

All of the principals, family caregivers, and HCPs had different information about the principal, his or her history, and the situations that arose during treatment. Each used the available information to make sense of the new situations and support their dynamic interaction regarding care transitions. For the principals, each had points within their episode of care that were outside of their memory. For some, this was their initial visit to the emergency room. For others, multiple readmissions began to blur with details of one hospital admission becoming

intermingled with another. Making sense, then, for the principals occurred without complete information about their recent clinical history.

Family caregivers often also lacked complete information about the principal. Whether they did not live with the principal and felt that they did not know what life was like in the home or whether they were not with the principal at the time of the events leading to admission, their view of the principal was not complete. Several acknowledged the points of view that they were lacking: "I find bits and pieces out. She'll come, one day, she'll say one thing, the next day, she won't." Another family caregiver was lacking information because she was out of town. "I was gone and my sister started staying over there." One principal who had been largely independent prior to the hospitalization did not share information widely with his family. It was not until they took him in their home that the severity of his decline was clear to them. This signaled a change in their approach to his care.

Family caregivers at times also viewed the principal differently than the principals viewed themselves or than the HCPs viewed them. Daughters viewed their mothers as focused on family with the principal's greatest joy from their grandchildren. While principals discussed the importance of family, none listed grandchildren as their greatest joy. Caregivers saw principals with advancing chronic illness as not taking adequate care of themselves in areas such as diet or exercise. Principals saw their decisions as a series of choices. The principals were happy with their choices.

HCPs viewed the principals as they were within the facility without recognition of acute changes related to memory loss or cognitive status. Even cases of stark change were minimized by HCPs caring for the principal for the first time. For example, on two separate occasions one principal was severely lethargic and unable to fully awaken. One HCP made sense

of the events through determining that the principal had poor perfusion and needed to be more active. Another determined that the principal had not slept well the night before. Neither probed more deeply for clinical explanation. In another example, in his initial hospitalization one principal was determined to be unable to return home because he was not able to adequately understand his own clinical care. Approximately two weeks later following readmission, another clinical team determined that the principal was prepared to discharge home with “any adult.”

Each of the agents, then, approached dynamic interaction related to care transition with important gaps in information related to the principal. Each also came to the interaction with different focus.

Focus of principals, family caregivers, and HCP. For each of the principals as they approached care transitions, focus was on returning home. This goal fit within their acceptable boundaries and their understanding of where they were clinically. Although the strength of their commitment to going directly home after their initial hospitalization was entirely personal, each openly expressed their expectation to return home, even though they knew that they would be going to SNF for rehabilitation. “I would like to be home.” Another principal stated, “I just want to get my strength back so I can go back home.” A third, “So, that’s my main objective is to get home.” The most dissatisfied of the principals said, “I think it’s [the SNF admission] just something I gotta go put up with for a week and a half, two weeks, get it done, get out of there, go home.”

For families, making sense regarding options for the principal were more variable. In their consideration of multiple priorities, they aimed to ensure that the principal was in a safe situation that the families could support. Therefore, their expectations and focus varied depending on the level of support they perceived the principal needed. Families were more

likely to suggest a more supportive option than the principal and often encouraged the principal to accept greater support. Mary's family caregiver described: "I guess my family has all discussed. We knew this point [was] coming. We've talked about it." A principal, who had suggested that he wanted to go home noted, "My [family caregiver] said that she just felt uncomfortable in having me home without having some additional...therapy."

Each of the families had significant concerns beyond care of the principal. These included care of family members with developmental diagnoses and mental illness. Family caregivers supported their own children through child care and help with significant projects. Some active in providing care for principals still worked in either full or part time roles and had children at home. As these family caregivers made sense of the principal's situation, they considered with these additional concerns in mind.

HCPs combined their assessment of the clinical requirements immediately post-discharge, the principal's cognitive and functional status during the hospitalization, and the principal's home situation, including the amount of available support, to recommend discharge location. This was the starting point for conversation and dynamic interaction. Following the first discussion, a social worker note reports that Mary's family "did not see the value of [home healthcare]." Based on this opinion, the social worker set up care transition to a SNF for rehabilitation. For Lou, the care manager note suggested that she asked the principal what level of support he thought he would need at hospital discharge. She focused solely on this level of care in planning for the care transition.

Each of the agents came to dynamic interactions related to care transitions with unique focus and information. The principals and family caregivers also came with long term relationships in various degrees of flux due to ongoing life transitions.

Familial approaches to principal support. Family caregiver(s) served as the main source of support and additional options for the principals throughout the cases. As such, families' approaches to care were important to meeting the principal's clinical and functional needs through care transitions in the context of life transitions.

Family support was not static, but changed dynamically as differences in principal needs or situations were recognized. Hospitalization or the event that caused the hospitalization was not always the trigger to recognition of changing needs. For principals with advancing chronic illnesses where hospitalization was common, family and principals themselves did not always recognize the event as indicative of advancing needs. In two initial hospitalizations, families approached the event as routine without substantial visitation or support changes. Likewise, for principals, where the hospitalization was the result of an acute event, the hospitalization may not have been indicative of long term change.

Patterns were identified in the dynamic interaction between family caregivers and the principal. These patterns have been termed "*Familial approaches to principal support.*" The approaches were not characterizations of rigid or permanent familial structures. Rather, within the cases multiple approaches were described and observed. These approaches, then, represent emergent patterns within the dynamic interactions characteristic of a moment in time. Within that moment, the emergent approach facilitated response to current principal needs. These principal needs varied both within and across cases, from minimal and short term support with driving or medication management to multiple, long term needs with home care, clinical and functional needs, and social engagement. As the principal needs changed, whether with improvement of acute illness or advancement of chronic illnesses, new approaches emerged within the family dynamics.

Familial approaches did not support all areas of the principal's life equally. Principals who needed significant support in some areas, such as home maintenance or medication management may have been independent in other areas such as coordinating interaction with HCPs or performing their own activities of daily living. Therefore, family responses to principal need were highly variable even within a single case.

Three distinct levels of principal need were identified: Independent, Inter-dependent, and Dependent. Principals moved between levels of need, both to higher and to lower levels, as clinical needs and their abilities to respond to them changed. As these changes were recognized, families modified their approaches to principal support. See Figure 4.2.

When principals were independent, they needed little to no support to manage their clinical needs and activities of daily living. Neither the principals nor the family considered the principal as dependent. Relationships in these cases varied by family member even within the same case. Some family members lived distant and interacted most commonly by phone. Local family members visited weekly or monthly. In some cases, one or both did not identify the principal as "ill" even to the point of downplaying diagnosed and treated chronic disease.

Independent principals managed their own medications and doctor's appointments. They cared for or arranged for professional help to care for their own homes. In response to a question about the amount of help he received prior to admission, one principal answered "...no help whatsoever...I got along fine, I was normal." Recently retired, this principal described his family visits in social terms. They "stop by...once a week or once every week and a half."

Interdependent cases were unique in that the principal and at least one of the family caregiver(s) lived together. Both the principal and the interdependent caregiver had chronic illnesses and both needed support in one or more areas. However, they were able to provide

support to each other enabling both to stay in the home. Whether formally discussed or the result of silent adaptation, these families had adjusted responsibilities to accommodate for deficits. One principal described a family member who lived with her: “She sometimes is worse off than I am, but we always manage...we have no problem. Everything goes fine. We get along good.” She described the balance of responsibilities “We live together and she kind of helps take care of me... usually she cooked and I washed the dishes.”

This approach worked well as long as both the principal and the caregiver were able to manage their duties. In this same case, at discharge from the SNF, the family caregiver took on new responsibilities: she managed medications and appointments, and took over all driving responsibilities. Shortly after the principal returned home, the family caregiver was admitted to the hospital. Another caregiver was asked to stay in the home.

When principals were dependent, they required support in one or more areas. Among the dependent principals, three familial approaches to principal support were identified within the cases. Each approach provided a unique level and type of support to the principal. Family caregivers adapted to increasingly more supportive patterns as principal chronic conditions encroached on independence. As acute issues resolved, less supportive approaches resumed. The four approaches to principal support included occasional or task-specific supporting, bracing, and cocooning.

As principals’ chronic disease advanced, **occasional or task-specific supporting** focused caregiver attention on the specific deficits. These episodes were short term instances of acute illness and recovery or long term support with specific activities. Examples seen within the cases were driving and completing home and /or yard care. Aside from these specific activities, these principals managed well. They functioned and remained socially satisfied within their own

homes. For one principal the initial hospitalization increased needs from independent to task-specific. During the hospitalization and following transition to SNF, the principal needed help taking supplies to the nursing home. He described his access to support: "I have a niece and nephew that will get me things..." Another described increasing difficulty with driving and shopping. "The only thing is probably I'll have my daughter drive me in the car, you know, until I get more strength."

As the principals' disease continued to advance or in response to an acute event, the number and intensity of their needs and the family caregivers' responsive supports increased. These increases advanced slowly enough in some cases as to be insidious. Family in these cases recognized the level of care they were providing had substantially increased only with rest associated with the hospital and SNF stay. "There's three of us retired so it has been not a big thing for the last maybe two years, maybe not even that long. Someone is always over making sure that we put out my mom's medications for the next day and help her with her insulin..." In this same case, family caregivers described supporting activities of daily living such as hair care; driving the principal to all appointments and shopping; care of the house including cleaning, laundry, and lawn care; and all activities that required walking outside the home such as taking out the garbage and getting the paper and mail.

Bracing was more organized and supportive than was occasional or task-specific supporting approaches, but was often not fully recognized by the principal. In bracing, one or more caregivers propped up the principal much as a brace provides strength and function to a limb. However, there was enough independent activity for the principal to recognize themselves as living well at home. One principal described this as "everything is set up at home." Given the multiple and substantial implications of his advanced chronic disease, his family supported all cooking, shopping, home care and maintenance, managing medication and driving. He did,

however, maintain the coordination and management of his HCP relationships and scheduling. This independence allowed him to recognize himself as functioning well. Another principal's family supported all interactions and decision making with HCPs. She maintained her sense of independence as she continued to plan and hold family dinners in her home. However, her adult children assisted with shopping before and cleaning after. The adult children more recently had also begun confirming that meals were adequately cooked prior to serving. (Mary) Nonetheless, she saw herself as "doing most of the cooking."

Bracing could provide for physical and/or cognitive support. However, for families that were bracing there were still areas of independence for the principal. When activities of daily living support was primary, caregivers were often not involved directly in coordination and planning with HCP. Rather, separate conversations occurred with the principal and caregiver(s) and the principal and HCP(s) to plan for care and care transitions. In one case, the principal had separate conversations with his family and HCPs, including a care manager and OT. Following, he asked to go to SNF for rehabilitation, reporting in separate instances that he was both not strong enough to go home and that his family caregiver was not comfortable with his physical care. In other situations, families coordinated with HCPs even as the principal was independent in other areas, such as cooking or maintaining their home. For example, a family caregiver described early conversations with her mother's primary care practitioner to support use of incontinence briefs and to initiate discussions regarding assisted living.

Cocooning implies family caregiver(s) entirely surrounding the principal to support and protect him or her. Within this pattern, the principal may have maintained some level of organizational awareness of multiple caregivers, caregivers may have organized among themselves or there may have been a single active caregiver. In cocooning, principal needs had advanced to a substantial level within multiple functional areas. Support included multiple types

of care: home, financial, physical and decision making, essentially leaving the principal with no clear areas of independence. For one principal cocooning remained in place for the majority of study participation. During this time, her family made all clinical and social decisions and informed the principal of the decisions afterward. Areas of independence had diminished as her ability to manage were impacted. For example, although she loved to sew, she was no longer able to thread the needle or manage even common problems with the machine. However, as she improved clinically and adjusted to life in long term care, she identified new areas of independence. She developed new hobbies to replace those that intensely engaged her prior. She increased her religious activities since this no longer required someone to drive her. And, she identified new activities, such as puzzles and group exercise sessions that held her attention. As she developed new interests, the family remained in strong bracing of her clinical and financial decisions, but the principal moved into independence in other areas.

Triggers for change in familial approaches. Movement from one familial approach to another, whether the change was for the short or longer term, was based upon triggers. Families did not consistently alter their approach to support as a direct response to the hospitalization. For some of these principals, hospitalizations were typical, occurring multiple times in the last year. For other, more independent principals, during hospitalization, families did not receive adequate information to indicate that the principal's level of independence had changed. Therefore, the hospitalization did not prompt a change in approach. As principals were more dependent, family caregivers were more aware of the principal's functional and cognitive abilities, prompting greater awareness of triggers.

Four triggers were seen within the cases. Most common was a clinical or functional necessity. In these cases, the principal experienced physical and/or cognitive changes that forced caregivers to work directly with the HCP and to step in to provide additional support.

Cognitive changes more readily triggered a change in approach during the hospitalization. However, functional or physical care needs often did not trigger a change until discharge planning revealed needs. In acute situations, the caregivers anticipated returning to “normal” once acute issues had resolved. Discharge from the SNF and clinical improvement worked as a trigger to reduce support at times. For example, in a case where an acute injury was the cause of admission, soon after discharge the principal began to reduce dependence on family.

For other principals and their families, lack of options for care that was agreeable to both the principal and the HCPs triggered further consideration and enhancement of family support. In these cases, the principals remained independent in guiding their care through the hospitalization. However, the principal did not find any of the presented post-discharge options acceptable. Additional family support in these care transitions increased available options. For example, a principal’s refusal to accept SNF placement prompted multiple discussions between the principal, family and multiple HCPs to identify an acceptable alternative. In the midst of these discussions, family recognized and responded to the need for a new approach.

A fresh look provided principals and families the opportunity to reconsider the approach to support used prior to hospitalization. For families who were providing significant support to the principal and for whom the advancement was gradual, a fresh look allowed the opportunity to consider whether that approach was sustainable. For those individuals who were beginning to doubt that current care was adequate, taking a fresh look allowed for re-consideration of the principal’s abilities and non-familial supports available. In the context of hospitalization, families were allowed time and objectivity to reconsider.

Finally, in some cases an outside prompt encouraged principals and / or family caregivers to recognize that something was not working in the current or planned approach.

These prompts came from an outside observer such as a HCP who encouraged the principal or the family member to think differently about their approach to support. These prompts came in the form of broad and philosophical discussions. These discussions reminded family of the principal's right to choice. More pragmatic discussions of requirements within various levels of care prompted both the principal and the family to realistically consider the principal's functional abilities.

Familial approaches to principal support addressed the principal's level of need. Upon recognition of dependence, family caregivers responded with what they perceived as adequate support. Principal responses to changes in familial approaches to support were variable. At times, principals embraced the change. At others, they resisted, viewing the support as a threat to acceptable boundaries. These dynamic family relationships played a role in determining how principal, family caregivers, and HCPs worked together at care transition. Timing of changes in familial approaches were related to recognition of triggers, not to care transitions. This lack of connection added to the complexity within dynamics between principals, family caregivers, and HCPs in care transition.

Principals, family caregivers, and HCPs working together. Principals, family caregivers, and HCPs worked together to care for the principal within and across facility care transitions. However, clinical and care transition conversations rarely involved principal, family caregivers and HCP equally or in only one conversation. Even when all were present for the initial conversation, sidebar conversations between two of the three substantially changed the interaction and the outcomes. For example, after being visited by the case manager and reporting a supportive environment, Lou had a conversation with his family caregiver. The caregiver voiced concern about discharge directly to home. After this conversation, he requested discharge to a SNF for rehabilitation. Likewise, Mary's family requested a private

meeting with HCPs. In this meeting, the family arranged for long term care placement. They informed the principal after the decision was made. In a final example, John's family members were never documented to have had a discussion on discharge options during his initial hospital admission. In the notes and in an interview regarding the principal's experience, only SNF placement was considered in spite of John's intense aversion.

In interacting with HCPs, principals and families narrowed their conversation to include only information that the principal and family considered clinically relevant to the HCP. Clinical history, decades long, was limited to the most recent events and symptoms. Information regarding the ongoing life transitions was not consistently shared. With histories of advanced chronic illnesses spanning multiple decades, principals and families attempted to frame the 'episode of care' to give adequate information, but without overloading with details. Social information was shared only when it was considered critical for the HCP to know. For example, when a principal was not able to return to her home, the family caregivers shared this life transition with the HCP. When a principal thought that support might be available to improve her home for discharge, she shared information about the home. The same principal declined to share the same information when she felt that the discharge to home (and her acceptable boundaries) might be threatened.

Likewise, HCPs focused the information that they shared with principals and families. This focus limited the potential to overload the principal or the family by tightening messages and sharing only well-framed options and clinical plans. This focus included limiting the HCP focus to clinical issues being addressed in the current admission. Broader issues, such as long term expectations, DNR status, and the progression of disease were largely avoided during hospitalization and the subsequent SNF admission unless the threat was considered imminent.

Patterns of dynamic interaction. Familial approaches to principal support strongly affected patterns of dynamic interaction between the principal, family and HCPs. In these cases, the principal and family rarely participated as distinct agents. Rather, with independent principals, family were, at times, excluded from the conversation. Likewise, with families using a cocooning approach, the principal differed to family or were completely absent from the interaction with HCPs. For this reason, the principal and family caregivers are described within this section as principal/family.

Three distinct patterns of interaction were identified between the principal/family and the HCP: tactical discussion, closed, and open. As with the Familial approaches to principal support, these were dynamic with changes to the pattern even within one care transition. Likewise, the principal / family at times used different patterns than the HCP, even in the same care transition. Therefore, like all interactions, these patterns were dynamic with any one representation accurate for only a moment in time. The three patterns varied in the amount and types of information shared, in the openness to new ideas, and in the style of interactions.

The first pattern of interaction, tactical discussion, was the most commonly seen. Here, both the principal/family and the HCP focused the information shared. All focused on clinically and socially relevant information deemed important for the planning and implementation of the care transition. As reported in a care manager's note: "Patient lives at home alone and prefers to return home at time of [discharge]. There are a couple of steps to enter the home and then it is one level. [Patient] uses a walker, able to dress herself and do her own bathing (daughter says they come in to help) patient still cooks (daughter stated patient does cook but there are concerns that she does not cook the food all the way through). Daughter states that family sets up patient's medications and they help with insulin / meds at home." Although the dynamic interaction between the principal and the family is seen in what each shared, there is no direct

appreciation of the life transition that the principal and family are attempting to cope with. For their part, the care manager and the social worker shared insight and support in the process of obtaining Medicaid and gaining transition to the preferred SNF.

In this pattern, there was limited openness to new ideas. Following through with the example above, the family was the dominant representative from the principal/family. They requested a SNF admission early on. The principal, although she preferred to go home, did not object and she qualified for the level of care. There was no discernable dissent to the plan and so the conversation quickly moved to a discussion of tactics for the care transition.

This pattern of dynamic interaction was seen most commonly within the care transitions. Whether from hospital to SNF/home or SNF to long term care/home, the principal/family and the HCP typically quickly agreed on the level of care at discharge. Once this agreement was achieved, the interaction moved to dealing with the tactics of the care transition. For a principal discharging from SNF to home, this included discussions regarding home healthcare and medications. The HCPs and the principal discussed each detail and determined what would occur at discharge: Home healthcare for therapy, yes. Stool softener, no. Flomax, no. Oxygen, let's evaluate for the next 24 hours. Within this care transition, as with all those seen in this pattern, the complex issues associated with such a discharge were put aside to focus on the details of treatment. The implications of life transitions were ignored and treatment at care transition was reduced to binomial decisions.

In the second pattern either the principal/family or HCPs or both were closed to sharing information and new ideas. However, the care transitions in which this type of dynamic interaction occurred still achieved principal and family agreement to the discharge plan. However, satisfaction was severely reduced. Information shared within this pattern of

interaction was hampered not only by the amount of information shared, but also what was heard. In the most troubling transition within this study, neither the principal nor the HCP fully shared with the other. Family in this care transition, were only minimally involved. The principal shared his disinterest in going to a SNF. However, he did not engage his family in the conversation. He had, up to this admission, been entirely independent. He remained alert and engaged. There was no trigger for a change in familial approach to principal support. The HCP, who saw their goal for the principal as keeping him “out of the hospital,” communicated this to the principal as “no options.” The HCP arrived at this conclusion based upon the principal’s limited social support and lack of ability to “understand complex care regimens.” At an impasse, the HCP message came through during multiple visits with the physician, care manager, social worker, all espousing the same message: you must go to a SNF for rehabilitation. The principal agreed, but with much resentment. “They’re coming up and telling me, okay, we have four other people that says that you need to be rehabbed before you go home. We don’t care what your opinion is, you’re going to go get their opinions and we don’t care what your opinion is.” He continued on “I think it’s you have to go because to HAVE to go, you have no other options.” The principal’s family was never asked to consider a greater role in his support and no options were considered beyond the SNF. Discussions were closed to all but typical discharge plans with obvious informal support mechanisms.

A second care transition following this pattern occurred from the SNF to home. No one was happy with the discharge. In this care transition, the SNF HCPs felt at a loss. Although the principal had met a number of his goals, clinical issues hampered his ability to perform in therapy. He plateaued and was told that he would need to discharge home because he no longer met level of care requirements. His family lost an appeal that the SNF staff hoped to help them win. The principal and family declined to private pay, but were uncomfortable with the

possibilities for them at home. With each closed to the options available to the other, the HCP staff resorted to discharging the principal home. He was back in the emergency room within 24 hours. The principal described the situation in our last interview, “[T]he occupational therapist have been working with me, you know, and so they said that they had done all that they could, so Medicare said, ‘well, we can’t cover him anymore in this facility...I came home on a Saturday and I called the visiting nurse that evening...so they came out that evening....and she said, ‘well, I guess if it were up to me, I would say to go to the emergency room...’”

The final, Open, pattern was inclusive of all voices. In this pattern, the principal, family and HCP all interacted dynamically together. The principal shared his narrowing possibilities AND his view of acceptable boundaries. The HCP and the family worked together and with the principal to identify an option that all considered safe and within acceptable boundaries. The dynamic had strong conflict at points. From an ICU bed the principal and his nephrologist discussed the need for dialysis and the clinical issues of choosing dialysis and those of choosing no dialysis. The principal took three days to determine that he would move forward with dialysis.

Care transition planning with consideration of life transition was terribly conflicted. The social worker who first approached the principal about his options at discharge noted, “Discussed his options, patient reported he ‘does not give a sh** and wants to return home with [home healthcare].” The principal flatly refused all placements other than the hospital or home. Over the course of his 12-day admission, his care transition was discussed and options considered by the care manager, social worker, and his nephrologist. He was evaluated by an acute rehabilitation facility who found his clinical status prohibitive. His family was engaged in the discussion, but had taken him home once before with frightening results. With discussion and engagement, the principal agreed to transition to a long term acute care hospital. This

option was never considered prior to his refusal to go to a SNF. In our last interview, he was delighted with the results and preparing to discharge home with much family caregiver support.

Summary of qualitative findings. Within this study of care transitions two distinct types of transitions were recognized, longer term, principal-centered life transitions and episodic HCP-centered processes of care transitions. Principals and their family caregivers complied with the need for care transitions, but the ongoing and complex life transitions held their attention. HCPs were often unaware of the substantial implication of the life transition for the principal. These HCPs focused on the complicated care transitions which held significant professional implications for them.

Principals, family caregivers, and HCPs engaged together to ensure care of the principal. Patterns in interaction were emergent and dynamic, changing from one moment to the next with family approaches to principal support influencing the dynamic between principal, family caregiver, and HCPs. Patterns in dynamic interaction between principal, family caregivers, and HCPs in care transition also emerged. More open patterns showed greater potential for tighter linking of life transition and care transition goals.

Quantitative Results

Aim 2. Quantitatively describe patient symptom distress, QoL, and selected indicators of unplanned health services utilization (i.e., emergency room, hospital readmissions) over time.

Embedded in this qualitative study of multiple care transitions was the quantitative measurement of factors that were considered important additions to the holistic description of care transitions: symptom distress, QoL, and unplanned healthcare utilization. Symptom distress and QoL were anticipated to provide insight into the patient experience. Likewise, unplanned

healthcare utilization, measured here as emergency room visits and readmissions, have been considered a sign of poor quality in care transition. In reality, unplanned healthcare utilization also increased the number of care transitions experienced.

As noted in Chapter 3, symptom distress and quality of life were assessed prior to the initial hospital discharge, after transition to the SNF, monthly during the SNF admission, and following discharge to home, either the principal's or a family caregiver's home or long term care. One principal provided data at all six assessment points during the maximum 120 days of study participation. Two principals completed four assessments (the initial hospitalization, twice after transition to the SNF, and once following discharge to home), and one completed three assessments (the initial hospitalization, after transition to the SNF and following discharge to home). Interviews are noted in chronological order from T1 to the final (T3, T4, or T6).

Within this section, I describe aggregate findings and individual trajectories of symptom distress and QoL over time. In addition, unplanned healthcare utilization are described in relation to the symptom distress and QoL results.

Symptom distress. As was noted in Chapter 3, the MSAS-SF measures the frequency of and distress related to 32 symptoms. Principals responded to questions regarding the presence and the degree of distress related to the symptoms. Absence of a symptom was scored as 0. Responses regarding degree of distress for physical symptoms ranged from 0.8 ("not at all") to 4 ("very much"). Frequency of psychological symptoms were reported on a scale from 1 ("rarely") to 4 ("almost constantly").

Overall, MSAS-SF results indicated low symptom distress with only one principal having any subscale scores higher than 2 on the 4-point scale. Specifically, Global Distress subscale results are as follows: Time 1, Global Distress mean was 0.95 ($SD=0.35$, $n=4$); Time 2, 1.06

($SD=0.43$, $n=4$); Time 3, 0.97 ($SD=0.77$, $n=4$); and Time 4, 0.89 ($SD=1.18$, $n=3$). Complete aggregate results of the MSAS-SF are reported in Tables 4.7. Individual trajectories are represented in Figures 4.3. Within the Global Distress subscale, cases (with one exception) closed with lower Global Distress than their early peak.

Physical Distress subscale results are as follows: Time 1, the Physical Distress mean was 0.68 ($SD=0.28$, $n=4$); Time 2, 0.82 ($SD=0.35$, $n=4$); Time 3, 0.75 ($SD=0.52$, $n=4$); and Time 4, 0.53 ($SD=0.66$, $n=3$). Complete aggregate results of the MSAS-SF are reported in Tables 4.7. Individual trajectories are represented in Figures 4.3. For the Physical Distress subscale, there was a tendency for an increase in distress following admission to the SNF, but decreasing distress thereafter.

Psychological Distress subscale results are as follows: Time 1, Psychological Distress mean was 1.02 ($SD=0.63$, $n=4$); Time 2, 0.89 ($SD=0.62$, $n=4$); Time 3, 0.95 ($SD=0.93$, $n=4$); and Time 4, 0.82 ($SD=1.28$, $n=3$). Complete aggregate results of the MSAS-SF are reported in Tables 4.7. Individual trajectories are represented in Figures 4.3. No trends were evident in the Psychological Distress subscale.

The most frequently reported physical and psychological symptoms (Table 4.8) were lack of energy, dry mouth, cough, pain, nausea, difficulty sleeping, shortness of breath, and feeling nervous. The most intensely distressing (Table 4.9) were dizziness, itching, vomiting, diarrhea, and "I don't look like myself." These most intensely distressing symptoms were among the least frequently reported. In fact, there was no overlap between the most frequently reported and the most intensely distressing symptoms. The number of reported symptoms peaked at SNF admission (Time 2). However, rate of symptom distress remained relatively stable and low throughout (See Table 4.10).

Quality of life. As was noted in Chapter 3, the McGill Quality of Life Questionnaire (MQoL) measures the principal's quality of life (QoL) or "subjective sense of wellbeing". Principals responded to questions regarding both symptoms and problems, and their feelings and thoughts over the past two days. Responses were on a scale from 0 to 10, where 0 indicates lack of the attribute and 10 indicates complete or extreme experience. During analysis, when needed, responses were transposed ensure that higher responses indicated higher quality of life. Four subscales, a global measure, and two single item subscales (SIS) are reported within this study. These are the Global MQoL, the Physical Symptoms subscale, the Psychological Symptoms subscale, the Existential Well-being subscale, the Support subscale and the Physical Well-being SIS, and the MQoL SIS.

The aggregated results for Global MQoL at each assessment point are as follow: Time 1 ($M = 5.95$; $SD = 1.65$; range = 4.22 – 7.57; $n = 4$); Time 2 ($M = 6.21$; $SD = 1.36$; range = 4.90 – 7.35; $n = 4$); Time 3 ($M = 6.50$; $SD = 1.65$; range = 4.03 – 7.27; $n = 4$); Time 4 ($M = 7.19$; $SD = 3.33$; range = 3.35 – 9.23; $n = 3$). Full results are summarized in Table 4.11. and individual trajectories are depicted in Figure 4.4. With the exception of the one principal who died, MQoL tended to be higher later in the study, although there was considerable individual variation.

During the MQoL Questionnaire, the principals were asked to list "physical symptoms or problems over the past two days." In administering the instrument, the PI defined and gave examples of what a symptom might be. Only one principal reported the same symptom or problem more than twice over time. "Problems" were more commonly described than "symptoms". Even when symptoms or problems were likely related to the same clinical concern, the reported physical symptoms were distinct. No principal listed three symptoms or problems at each measurement and one principal listed none on two separate occasions. See Table 4.12 for a list of physical symptoms or problems reported.

These principal-reported problems and symptoms are the basis for the Physical Symptoms subscale. The aggregated results for the Physical Symptom sub-scale at each assessment point are as follow: Time 1 ($M = 1.79$; $SD = 1.40$; range = 0.5 – 3.67; $n = 4$); Time 2 ($M = 2.75$; $SD = 1.85$; range = 1.0 – 5.0; $n = 4$); Time 3 ($M = 2.00$; $SD = 1.63$; range = 0 - 4; $n = 4$); Time 4 ($M = 4.33$; $SD = 0.94$; range = 3.67 – 5.0; $n = 3$). Full results are summarized in Table 4.11. and individual trajectories are depicted in Figure 4.4. These “physical problems and symptoms” were rated as more problematic to the principals’ QoL than any other of the sub-scales.

The aggregated results for the Psychological Symptoms subscale at each assessment point are as follow: Time 1 ($M = 7.63$; $SD = 3.03$; range = 3.25 - 10; $n = 4$); Time 2 ($M = 6.13$; $SD = 1.96$; range = 3.5 – 8.25; $n = 4$); Time 3 ($M = 7.81$; $SD = 2.67$; range = 4.0 – 10.0; $n = 4$); Time 4 ($M = 7.17$; $SD = 4.27$; range = 2.25 - 10; $n=3$). Full results are summarized in Table 4.11 and individual trajectories are depicted in Figure 4.4. Within psychological symptoms, there was an aggregate and within case trend showing a decrease in QoL related to psychological symptoms immediately after care transition to SNF. However, subscale scores generally increased in subsequent interviews.

The aggregated results for the Existential Well-being sub-scale at each assessment point are as follow: Time 1 ($M = 7.79$; $SD = 1.96$; range = 5.17 – 9.83; $n = 4$); Time 2 ($M = 7.58$; $SD = 2.23$; range = 5.50 – 9.83; $n = 4$); Time 3 ($M = 7.58$; $SD = 2.01$; range = 4.67 – 9.0; $n = 4$); Time 4 ($M = 7.50$; $SD = 3.63$; range = 3.33 – 10; $n = 3$). Full results are summarized in Table 4.11. and individual trajectories are depicted in Figure 4.4. No discernable trends were seen within the Existential Well-being sub-scale results.

The aggregated results for the Support sub-scale at each assessment point are as follow: Time 1 ($M = 7.75$; $SD = 2.22$; range = 5.0 - 10; $n = 4$); Time 2 ($M = 8.25$; $SD = 1.50$; range = 7.0 –

10.0; $n = 4$); Time 3 ($M = 8.38$; $SD = 2.02$; range = 5.5 - 10; $n = 4$); Time 4 ($M = 7.67$; $SD = 3.62$; range = 3.5 - 10; $n = 3$). Full results are summarized in Table 4.11. and individual trajectories are depicted in Figure 4.4. In the Support subscale, the general trend, both within case and in the aggregate was to stable or improving scores over time, with all but a single case ending the study with increased or stable measures.

The aggregated results for the Physical Well-being SIS at each assessment point are as follow: Time 1 ($M = 4.0$; $SD = 4.0$; range = 0 - 8 ; $n = 3$); Time 2 ($M = 6.0$; $SD = 2.65$; range = 3.0 – 8.0; $n = 3$); Time 3 ($M = 6.75$; $SD = 1.89$; range = 4.0 – 8.0; $n = 4$); Time 4 ($M = 7.67$; $SD = 3.21$; range = 4.0 – 10.0; $n = 3$). Full results are summarized in Table 4.11. and individual trajectories are depicted in Figure 4.4. In the Physical Well-being SIS, earliest measures tended to be lower than the final measure. However, during the cases, there was variation.

The aggregated results for MQoL SIS at each assessment point are as follow: Time 1 ($M = 4.75$; $SD = 2.75$; range = 2.0 – 8.0; $n = 4$); Time 2 ($M = 7.25$; $SD = 1.71$; range = 5.0 – 8.0; $n = 4$); Time 3 ($M = 7.0$; $SD = 2.16$; range = 4.0 – 9.0; $n = 4$); Time 4 ($M = 8.0$; $SD = 2.65$; range = 5.0 – 10.0; $n = 3$). Full results are summarized in Table 4.11 and individual trajectories are depicted in Figure 4.4. Within the MQoL SIS, both within case and across cases, there was a general trend of sustained and increasing QoL over time.

Unplanned health services utilization. As was described within the qualitative results, one principal avoided readmissions. The remaining three experienced six unplanned hospital readmissions and two emergency room visits that did not result in an admission. One principal experienced three readmissions resulting in care transitions to a second SNF and a long term acute care hospital. Another experienced three emergency room visits from a single SNF

resulting in two readmissions. The final principal experienced two emergency room visits resulting in one admission following discharge from SNF to home.

Five of the six hospital readmissions occurred within 30 days of the index hospitalization. The sixth readmission occurred within 90 days of the index hospitalization. All of the readmissions met criteria for clinical necessity as described within Chapter 3. See Table 4.13.

Unplanned health services utilization in relation to symptom distress and QoL. Visual graphical analysis was used to relate the symptom distress and QoL findings with the unplanned healthcare utilization, here measured as emergency room visits and hospital readmissions. For each principal, Symptom Distress remained low throughout the study. However, there were minor increases in measures of Symptom Distress before readmissions for Lou and John and for Eva's latter emergency room visit and readmission. There was not adequate sample size to determine statistical significance. (See Figure 4.5).

QoL measures were also related to unplanned utilization, as well. For each principal, the Physical Symptoms sub-scale shows strikingly lower scores than other sub-scales. This sub-scale is the mean of ratings of principal-identified symptoms or problems (none up to three) on a scale from "no problem" to a "terrible" problem. These problems or symptoms were affecting the principal's comfort or their ability to return home. However, there is not a consistent connection between the Physical Symptoms sub-scale and unplanned utilization. (See Figure 4.5).

Overall QoL trajectories appear unique for each principal. However, sub-scales, with the exception of the Physical Symptoms sub-scale, over time showed a tighter range of the sub-scales. For all but one, overall QoL improved over the cases. No connection between QoL and unplanned readmission could be identified. (See Figure 4.6).

Summary of quantitative results. In the interest of holistic description of multiple care transitions, symptom distress and QoL were measured at multiple intervals throughout each case. These measures were then related to unplanned healthcare utilization. Although the sample size was (by design) not adequate for measures of statistical significance related to symptom distress and QoL, within these four cases, practical significance seems minimal. However, the number of care transitions within these cases, 24, was striking.

Mixed Methods Analysis

Aim 3: Better understand patterns in the complexity of care transitions using cross-case comparisons in which each case includes both qualitative patterns and quantitative trajectories of symptoms distress, quality of life, and unplanned health services utilization over time. (Mixed methods merging of qualitative and quantitative results)

This mixed methods analysis included cross-case comparison of two cases purposefully selected to represent extremes in principals' care transition experiences. From the ten quantitative measures available for the mixed methods analysis, Global Symptom Distress was selected for integration with the qualitative results in the cross-case comparisons. Simultaneous integration of multiple quantitative measures with the qualitative results was beyond the scope of this analysis. Therefore this measure was chosen because it has potential for use in larger longitudinal studies for tracking symptom distress of older adults with variable conditions across multiple care transitions. Although small, such an analysis can serve as a "proof of concept" study intended to demonstrate the potential of cross-case mixed methods analyses in research on multiple care transitions among older adults with advancing chronic illness. I will explicitly use the lens of complexity science to address Aim 3. Specifically, care transitions will be examined in light of the complex adaptive systems in which they occurred and the outcomes

that emerged. First, I will describe the care transitions within each of two cases and the trajectory of Global distress (outcome) within each. Then, the patterns seen in life transitions will be described. Finally, the dynamic interactions related to care transitions, both familial approaches to principal support and dynamics of principals, families, and HCPs working together (multiple complex adaptive systems) will be considered. This cross-case comparison will provide a better understanding of the patterns within the complexity of care transition.

Patterns of care transitions. Across these cases, two strikingly different patterns of care transition emerged. The patterns resulted in differences both in number of and continuity across care transitions, but related most strongly to the experience of care transition felt by the principal. Both Mary and John had advancing chronic illnesses prior to the initial hospitalization. Both had engaged families. However, Mary was ‘carried’ through her care transitions while John was ‘tossed about.’

In the ‘**carried**’ pattern of care transitions, the principal was heavily supported. This support was seen in each of the facilities during the case and reported by more than one party prior to the case. The principal’s experience of being ‘carried’ through care transitions was founded on a deep sense of trust in those involved in her care. This consistent core group, including Mary’s family and her primary care physician, provided continuity to each transition and consistency within the CAS that was her patient-specific health system at each location. Being ‘carried’ does not imply a lack of conflict within the experience, but does imply thoughtful planning to minimize the negative effects related to change. Mary’s case is an exemplar of ‘carried’ transitions.

Over the course of 124 days, Mary transitioned the minimum three times: from home to hospital, hospital to SNF, and SNF to long term care. Prior to the hospitalization and through

each of the transitions, Mary's family was present and supportive of her many physical, social, and emotional needs. Mary accepted and depended on their support. She trusted her family to act in her best interest and referred others to them often. Mary and her family had a strong relationship with a primary care physician. They worked with this physician and his surrogates throughout the case to ensure that Mary's needs were met and her wants were not forgotten. This **consistent core group**, Mary's family caregivers and her physician, remained with Mary through each of the care transitions and supported her.

Prior to the hospitalization, Mary's family had begun to consider options for her care long term, in anticipation that her needs would exceed their ability to support at home. They had discussed this plan with her primary care physician, who was in agreement. As Mary, her family, and the HCPs moved through her hospitalization, SNF admission, and admission to long term care, the family's prior planning gave meaning to each care transition in relation to her life transition. This meaning allowed adequate support to 'carry' Mary through her care transitions.

In the **'tossed about'** pattern of care transitions, the principal was largely independent. Although family might have been present, they were engaged socially rather than as caregivers. They did not engage, whether due to lack of interest or lack of invitation, in dynamic interaction with HCPs related to care transitions, leaving the principal to consider and act on his own in discussion with HCPs, a **sole core agent**. The principal developed a sense of distrust in his HCPs as he struggled to both receive care from and act as an equal in discussions and negotiations regarding care transitions, all while acutely ill. Conflict was intense at times within the care transitions and resolution often related to which party relinquished first, rather than the attainment of a mutually agreeable solution. This, at least in part, related to the lack of a shared vision of clinical and support needs as John moved from one patient-specific health system (CAS)

to another as the only central and consistent agent. John's early care transitions serve as an exemplar of being 'tossed about' in care transitions.

John experienced a total of eight care transitions: from home to hospital #1, hospital #1 to SNF, and three readmissions (to hospital #1, and hospital #3), a stay in a hospital ER (#2) when an ambulance re-routed due to medical instability, and transitions to a caregiver's home, a second SNF, and a long term acute care hospital within a 59 day period. Through all but the final of these care transitions, John's family not only continued to act as though he were independent, but he also experienced tremendous discontinuity of clinical care providers. Although the first two readmissions were to the initial hospital, the primary medical and nursing teams changed with each admission. In addition, he was routed twice by ambulance to the nearest facility. Once he was stabilized and returned to the initial hospital. In his final readmission, he was seen by an entirely new clinical team in a third hospital. As John struggled to maintain his complete independence, he was unable to cognitively process all the events and began to mistrust his HCPs. Although his family finally did agree to support him, their roles were not agreed upon until his final hospital admission. To that point, negotiation regarding care transitions were tactical games of will. The 'loser' would give in to the others' plan first. No plan beyond the immediate clinical management existed. Until John's final readmission, each care transition came with little forethought beyond the next facility's ability to meet immediate clinical needs. Although John agreed to each of the care transitions, he did so only because he was told he "had no other options" not because he truly accepted the plan.

Care transitions outcome: Symptom distress. In spite of the described differences in care transitions patterns. Both Mary and John demonstrated similar trajectories in Global Distress, here termed **low and arcing**, in which distress rose briefly and then declined, never reaching a level that would be considered problematic. Global Distress Scores, as was reported

in Chapter 3, measure combined physical and psychological symptom distress. An unproblematic trajectory avoided the upper half of the distress scale and showed improvement over time, indicating an unproblematic experience with symptom distress.

Mary and John's specific trajectory in Global Distress showed the enhanced distress that both felt at transition from the hospital to SNF. Although John's scores were consistently higher than Mary's, neither showed concerning symptom distress. However, for both their Global Distress peaked at their transition from the initial hospitalization to the SNF and decreased thereafter. Cross-case comparison of the care transition patterns with the trajectory of Global Distress did little to illuminate further regarding patterns in the complexity of care transitions.

Patterns in Life Transitions. Although symptom distress outcomes did not illuminate the care transitions disparity between Mary and John, consideration of patterns in life transitions had the potential to add greater value.

Two patterns of life transition were seen within these two cases: gradual and abrupt. In **gradual** life transitions, over time, multiple small changes caused narrowing possibilities. However, with the gradual narrowing possibilities, threats to the principal's identity were minimal as the principals and family caregivers effectively adapted through multiple minor changes. Likewise, with the multiple small steps, acceptable boundaries were not directly challenged. Once again, allowing adaptation through more manageable transitions.

Mary's pattern of life transition was **gradual**. That is, her needs changed gradually over several years. For example, as she became less able to garden, she year-by-year planted less until she chose to plant only pots on her porch. As she gradually lessened the importance of gardening, she increased her sewing. Each provided for her a connection to her identity. Although she gave up driving well prior to the study, she increasingly found grocery and hobby

shopping more stressful. In response, her family caregivers took over partial tasks such as waiting in line while Mary waited in the car. Mary's health also gradually declined. Most recent to the initial hospitalization, she fell twice in the two weeks prior to admission. Her family increased support in response and talked frequently with Mary's primary care physician.

In addition to Mary's changing physical and clinical situations, she was also experiencing social and financial changes. She and her family knew prior to the initial hospital admission that she would not be able to stay in her home long term due to financial issues. Her family had begun to evaluate options, including working with a social worker in the primary care physician's office to initiate a Medicaid application. They had also begun to consider assisted living facilities. Mary's family had discussed the possibilities with Mary and all knew that a more supportive environment would be needed in the future. These many step-wise changes foreshadowed the need for greater change and triggered adaptation.

In **abrupt** life transitions, dramatic and rapid change occurred with little warning to the coming narrowing possibilities. This abrupt change provided a direct confrontation to the principal's identity and brought an immediate need to determine and manage acceptable boundaries. Adding to the insult, the abrupt life transition occurred in the context of acute illness in which the principal was functioning physically and cognitively below his norm.

John's pattern of life transition was **abrupt**. When John arrived to the clinic visit that would lead to an extended admission, he came with symptoms of a viral illness. He never anticipated admission, and much less so the extended stay and SNF admission that followed. Likewise, his relationship with his family was social. They visited, but John did not need support on any routine basis. He was independent prior to the admission. John was also experiencing social and financial changes, but in a much different way than Mary. He had recently retired and

was planning for a future of fishing, working on cars, and reading. He was “normal” in that he was an independent adult. His financial future was secure and he enjoyed his ability to support his family with such things as college tuition.

Neither John nor his family were able to recognize and adapt adequately within a single -- or even several -- hospital admissions to the dramatic nature of his life transition. In the context of hospitalization for acute illness, John showed little awareness of the change. He considered the problem to be the HCPs who insisted that he go to a SNF rather than an abrupt change in his abilities. Rather than bring his family into the discussions, he chose to work independently with the HCPs, as he had always done. Therefore, his family had no trigger to change their approach to principal support and he remained the sole core to his patient-specific health systems.

Life transition patterns triggered (or did not trigger) changes in familial approaches to principal support. These adaptations, whether substantial or minimal, had tremendous implications for care transitions through dynamic interactions. In the next section, I will complete the cross-case comparison of care transitions in relation to these dynamic interactions.

Care transitions in relation to Dynamic Interactions. Identified patterns of dynamic interactions were at opposite ends of a spectrum: aligned and misaligned. **Alignment** relates to the connection of the principal’s needs with the support available to him or her. When a principal’s needs, whether great or quite small, were aligned with the level of familial support provided, this support enabled the principal to be independent to the extent of his or her ability. However, when familial support was either too intense or too limited, principals felt added stress as they worked to maintain identity and manage acceptable boundaries within the

narrowing possibilities of their life transition. When familial support was too intense, a principal's limits of acceptable boundaries and ability to maintain their identities were challenged as they struggled to balance the importance of the relationship with their desire to work through the life transition to their fullest abilities. However, when too little support was available, the principal was unable to perform adequately, making them vulnerable to any number of threats: clinical, physical, social, and emotional. Although alignment related most completely to familial support of principal needs, the state of this alignment had dramatic effect on principals, families, and HCPs working together.

Mary's case presents a strong example of **aligned** dynamic interactions throughout. In contrast, alignment did not occur until the end of John's case. When aligned, familial approaches to principal support matched the principal's needs, allowing for independence in areas of principal strength and support in areas of need. For example, Mary's family remained in a state of cocooning throughout most of the case. Mary's trust in her family and disinterest in coordinating with HCPs or dealing with finances made the cocooning important to ensuring Mary's safety. However, Mary was independent in managing her day within long term care. This independence and her intense trust of her family allowed her to accept long term care and maintain her identity. John planned to remain strong in his coordination of HCP interaction, but engaged tremendous familial support in managing his home, driving him to appointments, and monitoring his fluid and glucose balances. In this alignment, John shared information with both his family and HCPs, enabling adequate support to ensure his safety in his home environment.

John's early case serves as an exemplar of **misaligned** dynamic interactions. Although John was strongly independent and his family aligned in their social relationship prior to his initial hospital admission, his dramatic and abrupt change in needs during the initial hospital admission did not trigger the family to change their approach to principal support. As he fought

to maintain his identity and to establish and protect acceptable boundaries, John did so without adapting to the life transition he was undergoing. He considered the narrowing possibilities to be related to the HCPs, not his needs. As such, he rigidly set acceptable boundaries that did not include nursing home care and he took each HCP statement of his need for SNF care as an affront to his independent identity.

These differences in alignment of familial approaches with principal need also affected the dynamic interactions between principal, family, and HCPs working together at each transition. Mary's cocooning family interacted in Mary's behalf with HCPs throughout the case. Although the dynamic interactions with HCPs remained consistently in a tactical approach, Mary's clinical needs were met by the HCPs and her social and support needs were met by her family. Mary considered her movement into long term care "sad," but she adapted to the change with an increase in at least one area of independence: managing her daily activities.

The abrupt nature of John's case also affected dynamic interactions. John entered his initial hospitalization entirely independent; his family was absent from the dynamic. As HCPs began working with John to plan for discharge, the dynamic interaction quickly closed to discussion – John insisted that he would go home; HCPs insisted that he needed SNF care. Each side stated their opinions until John relented begrudgingly to SNF admission. In the SNF, John remained independent. At the onset of new symptoms, he determined that he would be readmitted, quickly closing discussion. HCPs notified his family after the ambulance left. In this first readmission, John used tactical discussion with the hospital HCPs to manipulate discharge to a family member's home. Discussion remained tactical. Family members, still with no trigger to modify their familial approach to principal support, remained in a minimally supportive stance. Within days, John returned to the hospital acutely ill. During this admission, the dynamic shifted. A family member's voice was heard somewhat equally with John's. John acquiesced

decision making regarding care transitions to this family member. Once again, closed discussion dominated, leading to another care transition unrelated to John's life transition.

During John's final readmission within the study, there was a dramatic shift in dynamic interactions and familial approach to principal support. When John adamantly and defiantly refused to transition to any nursing home, HCPs reached out to John's family member. Their conversations triggered a change in familial approach to principal support that developed over the course of the hospitalization and the following transition to a long term acute care hospital. John's family moved into a strong bracing approach with multiple caregivers involved and providing for his many needs. John, his family caregivers, and a representative of the medical team worked together to safely provide for his care in a manner that allowed him to remain within acceptable boundaries in spite of his narrowing possibilities of his life transition. The life transition and the care transition finally connected through this alignment of familial approach and dynamic interaction.

Patterns in the Complexity of Care Transitions. Care transitions within this study were predominantly complicated, with many details to manage within regulatory and best practice boundaries. As such, an outcome measure inclusive of physical and psychological symptom distress was a logical choice to demonstrate patient adaptation. Global distress demonstrated a low, arcing trajectory indicating adequate adjustment within the SNF. However, when considered in light of a holistic view of the cases, this logical interpretation was found to be overly simplistic. In fact, the principals were interacting within multiple complex adaptive systems: multiple facilities with multiple HCPs and within families. Each of these systems were in constant movement as they adapted to the many clinical, care and life transitions simultaneously occurring. When a core CAS moved with the principal, "carrying" her across multiple care transitions, and aligning dynamic interactions to the principal's narrowing

possibilities, identity, and acceptable boundaries, no readmissions occurred. When no core CAS existed, chaos ensued, with conflict, misaligned interactions, and multiple readmissions. By sheer force of will, the principal brought the about a better-aligned CAS, but this was a slow and difficult process.

Although Mary and John had similar Global distress trajectories, their care transition experiences were starkly different. These differences illuminated through consideration of the qualitative experiences within the cases. Dynamic interactions between principal, family caregivers, and HCPS were markedly different within and between cases depending upon the alignment of familial approaches to principal support and the principal's need for support. When familial support was aligned with principal need, dynamics in principal, family caregivers, and HCPs working together were more open, leading to care transitions that considered the ongoing life transition. Care transitions that related to the ongoing life transitions did not challenge principal acceptable boundaries or threaten identities. In addition, narrowing possibilities were more effectively managed. In fact, Mary and John both experienced a decrease in their narrowing possibilities when open patterns of dynamic interaction were present.

Chapter 4: Tables and Figures

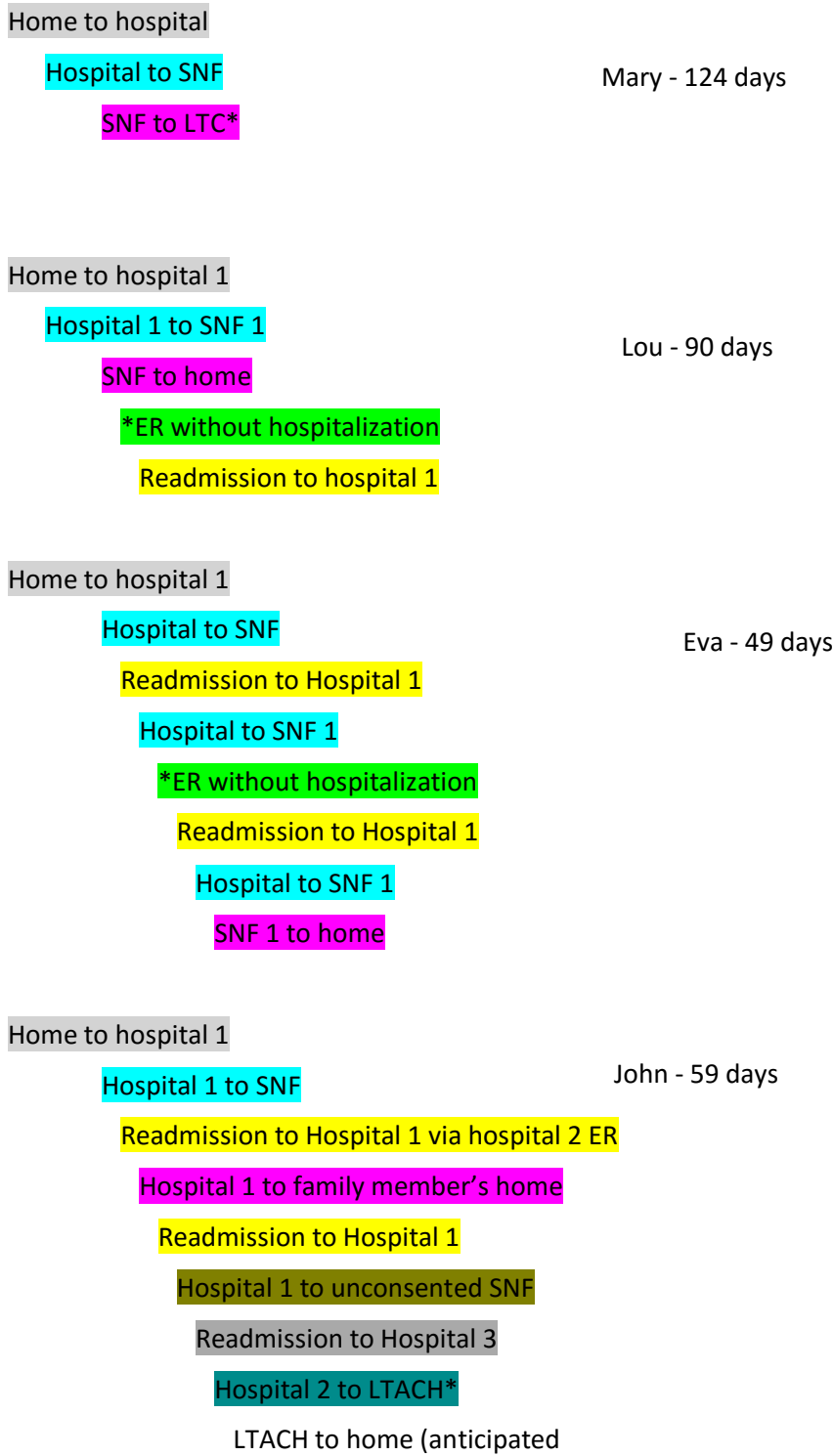
Table 4.1 Participant Demographics

Study Arm	N	Age	Gender	Race	Education
Expert HCP	30	≤ 30 = 5 31–40 = 9 41–50 = 4 51–60 = 8 61–70 = 4	F = 27 M = 3	White, not Hispanic = 26 African American = 3 Bi-racial = 1	Some college, less than Bachelors = 4 Bachelors = 12 Masters = 13 Post- Masters = 1
Direct care HCP	15	≤ 30 = 2 31–40 = 3 41–50 = 3 51–60 = 4 61–70 = 3	F = 13 M = 2	White, not Hispanic = 13 African American = 2	Some college, less than Bachelors = 4 Bachelors = 7 Masters = 4
Principal	4	≥ 65 yrs	F = 2 M = 2	White, not Hispanic = 4	Did not complete high school = 1 High school = 1 Bachelors = 2
Family caregivers	2	≥ 40 yrs	F = 2	White, not Hispanic = 2	Some college, less than Bachelors = 1 Some graduate school = 1

Table 4.2: HCP Roles and Experience

Study Arm	Role	Experience (years)
Expert HCP	Staff nurse = 2 Staff PT = 1 Case Manager = 5 Social Worker = 8 Chaplain = 2 Managerial role = 6 NH Administrator = 1 NH Admissions = 3 APRN = 2	0 < 2 = 3 2 < 5 = 4 5 < 10 = 7 10 < 20 = 6 20 < 30 = 6 ≥ 30 = 3 Missing = 1
Direct Care HCP	Staff nurse = 3 Case Manager = 1 Social Worker = 4 Chaplain = 1 Managerial role = 5 APRN = 1	0 < 2 = 3 2 < 5 = 2 5 < 10 = 3 10 < 20 = 3 20 < 30 = 3 ≥ 30 = 1

Figure 4.1: Flow Diagram of Care Transitions



*LTACH = long term acute care hospital LTC = long term care ER = emergency room

Table 4.3 John - Care Transitions and Care Providers

John Day	-21	0	8	8	13	18	20	24	37
	initial hosp	SNF - 1	ER - 1	hosp - 1	niece home	hosp - 1	SNF - 2	hosp - 2	LTACH
Care providers - central	principal - primary cardiac surgery team (surgeons, residents, CM, SW, patient teaching staff), PCP team, nephrologist	principal - PCP (Medical Director from Hosp 1), Resident, ADON (LPN) Direct care staff	principal - EMT / ambulance crew, ER HCP (phone conference with hosp 1 HCP)	principal - niece - primary Fam Med - Seen and treated by Surg Uro - PT	principal - niece (other family members?) - VNA planned, visit notes not accessible. -	principal - niece - Primary Fam Med - HF team, PT, OT, SW, CM,	principal - niece - Clinical team not identified.	principal - niece - primary changed over the course of admission - PCP, pulm, nephro, others active / consulted: cardio, CM, SW, consult by inpt rehab	principal - niece - extended family - primary is nephrology, cardiology, PCP all followed from IMC. PA from LTACH coordinates. PT, OT, care manager, direct staff all new.
Care providers - central facility-based	direct care staff	direct care staff	direct care staff	direct care staff		direct care staff	direct care staff	direct care staff - All new medical team due to transfer to new facility.	direct care staff
	clinic to ER to floor	medivan to unit	ambulance to ER to stablize	ambulance to ER to floor		clinic to ER to floor		ambulance to ER to ICU	
Care providers - periphery	niece / nephew	niece / nephew - Cardiac surgery, Cardiology, Nephrology, Urology	niece / nephew	nephew	nephew - PCP, card (HF), card surg, nephro, uro surg, DM mngmt, all follow at intervals	nephew	nephew	nephew - surgery (for permacath).	
Comments			To closest facility.	To MC due to preferred.				To IMC due to closest facility	
				Niece was primary only at point of discharge					

Table 4.4: Mary – Care Transitions and Care Providers

Mary			
Day	-6	0	33
	initial hosp	SNF	LTC
Care providers - central	principal - family core - primary PCP with longstanding relationship with principal and family from ER staff - CM, SW	principal - family core - NP contracted by ongoing PCP - SW, Care Planning attendees - Chaplain	principal - family core - Physician from PCP office - Chaplain
Care providers - central facility-based	direct care staff, includes PT, OT, RT	direct care staff includes PT, OT	direct care staff, PT, OT limited to group classes
	ER to floor	medivan to unit	wheelchair to unit
Care providers - periphery	legal support for Medicaid application, etc.	PCP in contact with NP via phone	Same PCP practice covers, but not same PCP. No evidence of ongoing contact with previous primary.

Table 4.5 Lou – Care Transitions and Care Providers

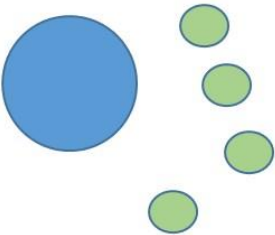
Lou					
Day	-9	0	54	54	84
	initial hosp	SNF - 1	home	ER - 1	Hosp 1
Care providers - central	principal - Wife / daughter - primary: PCP, Pulmonary, nephrologist (both new), cardiologist (since 2010)	principal - wife / daughter - PCP in to NH weekly, care planning participants,	principal - wife / daughter -	principal - wife / daughter - ER direct care staff	principal - wife / daughter (son?) - ER direct care staff to the PCP from initial adm., EP card from within current card group), Nephrology consult (new), ophthalmology consult (new), CRNA (new), pulm (new) PharmD (med dosing) chaplain at end of life -
Care providers - central facility-based	direct care staff	direct care staff	HHC	ER direct care staff	direct care staff
	ER to ICU to floor	transport to SNF			ER to floor to ICU
Care providers - periphery	son	son	son	son	son
Comments		follow up appointments scheduled with: Pulm, card. Principal saw the nephrologist in his office once. All others cancelled due to isolation precautions.	follow up appointments with PCP, cardio and nephro from this hospitalization.	Per ED staff direction, he made an appointment with the wound care specialist who followed him when he hurt his knees last year.	Plan noted in chart to return to previous nephrologist on discharge.
		Nephrology followed after initial visit via phone. Anticoagulation managed by pharmacist per physician order.		After seeing the cardiologist, a holter was placed. He has an appointment with an EP from his cardio office.	

Table 4.6 Eva - Care Transitions and Care Providers

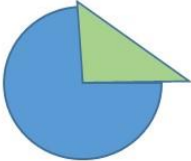
Eva									
Day	-23	-19	0	5	8	20	24	28	38
	initial hosp	hosp 1 inpt rehab	SNF - 1	hosp 1	SNF - 1	ER - 1	Hosp 1	SNF-1	home
Care providers - central	principal - daughter (local) - primary: Ortho surg, PCP	principal - daughter(s) one at a time - primary: Rehab physicians. Consults: pulmonary, ID, medical neuro, urology	principal - daughter(s) one at a time - PCP contracted to NP coverage, care planning participants,	principal - daughter(s) one at a time - ER staff to PCP, med neuro, pulm, cardio consult, ST consult	principal - daughter (local) contracted NP -- - ortho surg f/u appts direct PT, urology clinic visit - sent to ER from clinic	principal - daughter (local) - ER direct care staff (arrived from Uro clinic)	principal - daughter (local) - ER direct care - PCP surrogate at adm PCP w/ relationship returned during hosp.; pulm consult (new)	principal - daughter (local) - contracted NP	principal - daughter (local) - procedural neuro, follow up visits scheduled with PCP, pulm, rehab
Care providers - central facility-based	direct care staff	direct care staff	direct care staff	direct care staff	ER direct care staff	direct care staff	direct care staff	direct care staff	HHC
	ER to floor (OR)	inpatient rehab within same facility	transport to unit	ambulance to ER to ICU	transport to original SNF room	clinic to ambulance to ER to transport to same SNF room	ambulance to ER to floor	transport to same SNF room	private car
Care providers - periphery		neuro procedure MD for planning; PCP	PCP - by phone with NP		daughter (away)	daughter (away)	daughter (away)	daughter (away)	daughter (away)
Comments			follow up appointments with neuro procedure, pulm, ortho surg, uro, rehab medicine				follow up appointments w/ original pulm rehab med, peocedural neuro	procedural neuro	
		vomitting hours before discharge to the SNF (days before, SNF transfer cancelled due to "out of it" diagnosed with pneumonia)		Day before "sleeping excessively" de-saturating night before during sleep.					

Figure 4.2: Familial Approaches to Principal Support

Independent:

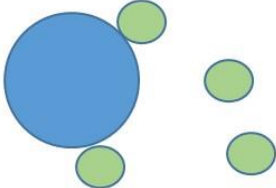


Interdependent:



Dependent:

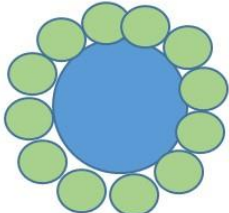
Occasional or Task-specific:



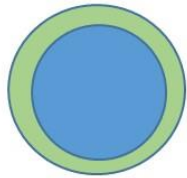
Bracing:



Cocooning



Cocooning (second adaptation):



Blue = principal

Green – family caregiver(s)

Table 4.7: Symptom Distress across Care Transitions

Global Distress						
	T1	T2	T3	T4	T5	T6
John	0.88	1.68	1.12			
Eva	0.82	0.72	0.40	0.16		
Mary	0.64	0.82	0.36	0.26	0.08	0.16
Lou	1.46	1.00	2.00	2.26		
n	4.00	4.00	4.00	3.00	1.00	1.00
mean	0.95	1.06	0.97	0.89		
range	0.64 - 1.46	0.72 - 1.68	.36 - 2.0	.16 - 2.26		
SD	0.35	0.43	0.77	1.18		

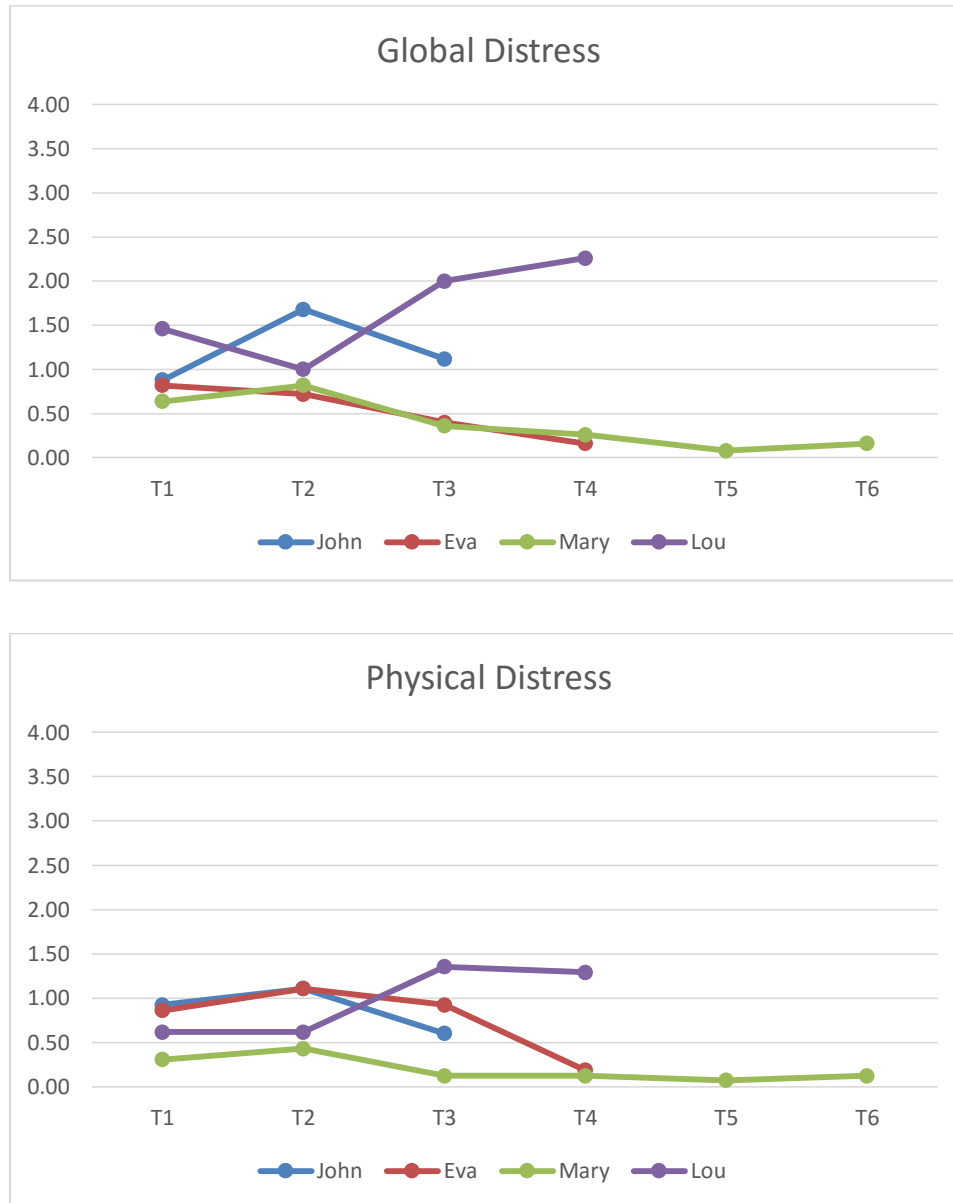
Physical Distress						
	T1	T2	T3	T4	T5	T6
John	0.92	1.11	0.60			
Eva	0.86	1.11	0.92	0.18		
Mary	0.31	0.43	0.12	0.12	0.07	0.12
Lou	0.62	0.62	1.35	1.29		
n	4.00	4.00	4.00	3.00	1.00	1.00
mean	0.68	0.82	0.75	0.53		
range	.31 - .92	.43 - 1.11	.12 - 1.35	.12 - 1.29		
SD	0.28	0.35	0.52	0.66		

Psychological Distress						
	T1	T2	T3	T4	T5	T6
John	0.93	1.20	1.20			
Eva	0.43	0.00	0.00	0.00		
Mary	0.80	0.97	0.47	0.17	0.00	0.00
Lou	1.90	1.40	2.13	2.30		
n	4.00	4.00	4.00	3.00	1.00	1.00
mean	1.02	0.89	0.95	0.82		
range	.43 - 1.90	0 - 1.4	0 - 2.13	0 - 2.3		
SD	0.63	0.62	0.93	1.28		

Theoretical range for all sub-scales is 0 – 4. Higher scores indicate higher distress.

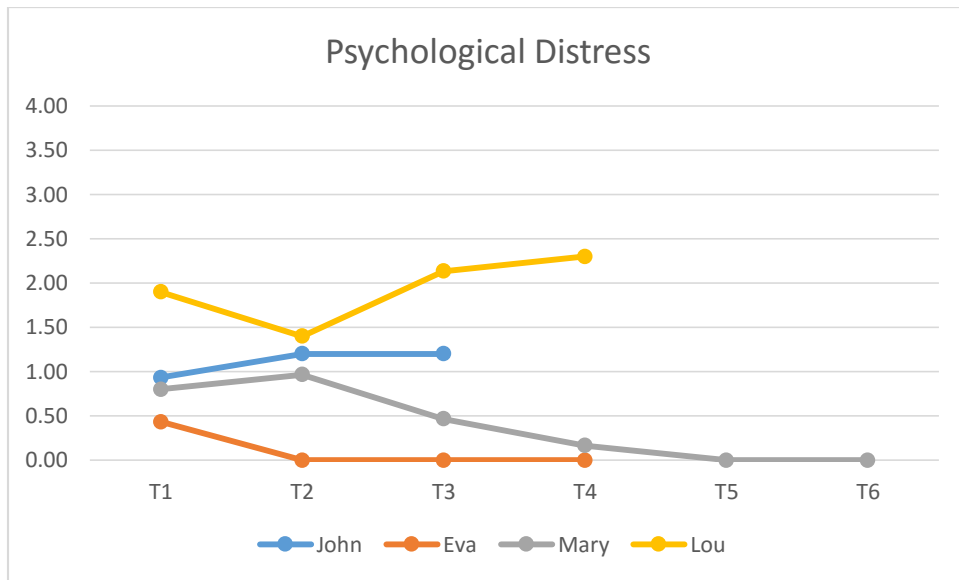
T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

Figure 4.3: Symptom Distress Trajectories across Care Transitions



Theoretical range for all sub-scales is 0 – 4. Higher scores indicate higher distress.

T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge



Theoretical range for all sub-scales is 0 – 4. Higher scores indicate higher distress.

T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

Table 4.8: Frequency of Reported Symptoms

	≥ 10	8 - 9	6 - 7	4 - 5	3-2	0-1
Physical Symptoms	<ul style="list-style-type: none"> • Lack of energy • Dry mouth 	<ul style="list-style-type: none"> • Cough • Pain • Nausea • Difficulty sleeping • Shortness of breath 	<ul style="list-style-type: none"> • Difficulty concentrating • Changes in skin • Swelling of arms or legs • Feeling drowsy 	<ul style="list-style-type: none"> • Feeling bloated • Numbness / tingling in hands and feet • Problems with urination • Diarrhea • Problems with sexual interest or activity • Lack of appetite • Weight loss 	<ul style="list-style-type: none"> • Sweats • Itching • Difficulty swallowing • Constipation 	<ul style="list-style-type: none"> • Mouth sores • Vomiting • Dizziness • Changes in the way food tastes • “I don’t look like myself” • Hair loss
Psychological Symptoms		<ul style="list-style-type: none"> • Feeling nervous 	<ul style="list-style-type: none"> • Feeling sad 	<ul style="list-style-type: none"> • Worrying • Feeling irritable 		

Table 4.9: Intensity of Reported Symptom Distress

	≤ 1.0	1.01 - 2	2.01 - 3	3.01 – 3.99	4.0
Physical Symptoms	<ul style="list-style-type: none"> • Weight loss • Mouth sores • Change in the way food tastes 	<ul style="list-style-type: none"> • Difficulty swallowing • Shortness of breath • Feeling drowsy • Cough • Difficulty sleeping 	<ul style="list-style-type: none"> • Problems with urination • Nausea • Changes in skin • Pain • Dry mouth • Feeling bloated • Constipation • Difficulty concentrating • Sweats • Problems with sexual interest or activity • Lack of energy • Swelling of arms or legs 	<ul style="list-style-type: none"> • Itching • Vomiting • Diarrhea • “I don’t look like myself” 	<ul style="list-style-type: none"> • Dizziness
Psychological Symptoms		<ul style="list-style-type: none"> • Feeling sad • Feeling irritable 	<ul style="list-style-type: none"> • Worrying • Feeling nervous 		

Table 4.10: Number of Symptoms and Degree of Symptom Distress across Time

	T1	T2	T3	T4	T5	T6
Principals interviewed	4	4	4	3	1	1
difficulty concentrating	3 / 2.1	2 / 2.0	1 / 3.2	1 / 3.2	0	0
pain	2 / 2.8	3 / 1.9	1 / 2.4	1 / 2.4	0	1 / 1.6
lack of energy	3 / 2.4	3 / 1.6	3 / 2.1	2 / 2.0	1 / 0.8	0
cough	3 / 2.1	2 / 2.0	2 / 0.8	2 / 1.6	0	0
changes in skin	1 / 4.0	2 / 3.2	3 / 2.1	1 / 1.6	0	0
dry mouth	2 / 2.4	3 / 2.4	3 / 2.9	2 / 1.6	0	0
nausea	2 / 3.2	3 / 2.1	2 / 2.8	1 / 3.2	0	0
feeling drowsy	2 / 1.6	2 / 1.2	1 / 2.4	1 / 2.4	0	0
numbness/tingling in hands and feet	1 / 1.6	1 / 2.4	1 / 1.6	1 / 2.4	0	0
difficulty sleeping	2 / 2.0	2 / 1.2	3 / 1.6	1 / 1.6	0	0
feeling bloated'	2 / 2.4	2 / 2.4	1 / 2.4	0	0	0
problems with urination	1 / 3.2	3 / 2.7	0	0	0	0
vomiting	0	1 / 3.2	0	0	0	0
shortness of breath	3 / 2.1	2 / 2.0	2 / 1.2	1 / 1.6	0	0
diarrhea	1 / 2.4	1 / 3.2	1 / 4.0	1 / 3.2	0	0
sweats	1 / 1.6	1 / 1.6	0	1 / 4.0	0	0
mouth sores	0	1 / 0.8	0	0	0	0
problems with sexual interest or activity	1 / 3.2	1 / 0.8	1 / 2.4	1 / 2.4	0	0
itching	1 / 4.0	0	1 / 2.4	1 / 3.2	0	0
lack of appetite	0	2 / 0.8	1 / 2.4	1 / 2.4	0	0
dizziness	0	0	1 / 4.0	0	0	0
difficulty swallowing	0	2 / 2.0	0	1 / 1.6	0	0
change in the way food tastes	0	0	1 / 0.8	0	0	0
weight loss	0	1 / 0.8	2 / 1.2	1 / 0.8	0	0
hair loss	0	0	0	0	0	0
constipation	1 / 3.2	1 / 1.6	0	1 / 2.4	0	0
swelling of arms or legs	2 / 2.0	2 / 1.6	2 / 3.6	1 / 0.8	0	0
"I don't look like myself"	0	0	1 / 3.2	0	0	0
feeling sad	3 / 1.3	2 / 1.5	1 / 2.0	1 / 3.0	0	0
worrying	1 / 2.0	2 / 2.0	1 / 2.0	1 / 3.0	0	0
feeling irritable	2 / 1.5	1 / 1.0	1 / 2.0	0	0	0
feeling nervous	2 / 2.5	3 / 2.3	2 / 2.0	2 / 2.0	0	0
total / mean distress	42 / 2.27	51 / 2.0	39 / 2.25	27 / 2.13'	0	1 / 1.6

Table 4.11: QoL across Care Transitions

Global MQoL						
	T1	T2	T3	T4	T5	T6
John	4.88	5.17	7.52			
Eva	7.13	7.42	7.20	9.00		
Mary	7.57	7.35	7.27	9.23	9.94	7.71
Lou	4.22	4.90	4.03	3.35		
n	4.00	4.00	4.00	3.00	1.00	1.00
mean	5.95	6.21	6.50	7.19	9.94	7.71
range	4.22 - 7.57	4.90 - 7.35	4.03 - 7.27	3.35 - 9.23		
SD	1.65	1.36	1.65	3.33		

QoL - Physical Symptoms						
	T1	T2	T3	T4	T5	T6
John	0.50	3.50	4.00			
Eva	1.00	1.00	0.00	5.00		
Mary	2.00	5.00	2.00			2.00
Lou	3.67	1.50	2.00	3.67		
n	4.00	4.00	4.00	3.00	1.00	1.00
mean	1.79	2.75	2.00	4.33	none listed	2.00
range	.5 - 3.67	1.0 - 5.0	0 - 4	3.67 - 5.0		
SD	1.40	1.85	1.63	0.94		

QoL - Psychological Symptoms						
	T1	T2	T3	T4	T5	T6
John	9.25	6.50	9.25			
Eva	10.00	8.25	10.00	10.00		
Mary	8.00	6.25	8.00	9.25	10.00	9.00
Lou	3.25	3.50	4.00	2.25		
n	4.00	4.00	4.00	3.00	1.00	1.00
mean	7.63	6.13	7.81	7.17		
range	3.25 - 10	3.5 - 8.25	4.00 - 10	2.25 - 10		
SD	3.03	1.96	2.67	4.27		

Theoretical range for all sub-scales is 0 – 10. Higher scores indicate higher QoL.
T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

QoL - Existential Well-being						
	T1	T2	T3	T4	T5	T6
John	7.67	5.83	7.83			
Eva	8.50	9.83	9.00	10.00		
Mary	9.83	9.17	8.83	9.17	9.83	9.83
Lou	5.17	5.50	4.67	3.33		
n	4.00	4.00	4.00	3.00	1.00	1.00
mean	7.79	7.58	7.58	7.50		
range	5.17 - 9.83	5.50 - 9.83	4.67 - 9.0	3.33 - 10		
SD	1.96	2.23	2.01	3.63		

QoL - Support						
	T1	T2	T3	T4	T5	T6
John	7.00	7.00	8.50			
Eva	9.00	10.00	10.00	10.00		
Mary	10.00	9.00	9.50	9.50	10.00	10.00
Lou	5.00	7.00	5.50	3.50		
n	4.00	4.00	4.00	3.00	1.00	1.00
mean	7.75	8.25	8.38	7.67		
range	5.0 - 10	7.0 - 10	5.5 - 10	3.5 - 10		
SD	2.22	1.50	2.02	3.62		

QoL - Physical Well-being SIS						
	T1	T2	T3	T4	T5	T6
John	0.00	3.00	8.00			
Eva		8.00	7.00	10.00		
Mary	8.00		8.00	9.00		
Lou	4.00	7.00	4.00	4.00		
n	3.00	3.00	4.00	3.00	0.00	0.00
mean	4.00	6.00	6.75	7.67		
range	0.0 - 8.0	3.0 - 8.0	4.0-8.0	4.0-10.0		
SD	4.00	2.65	1.89	3.21		

Theoretical range for all sub-scales is 0 – 10. Higher scores indicate higher QoL.

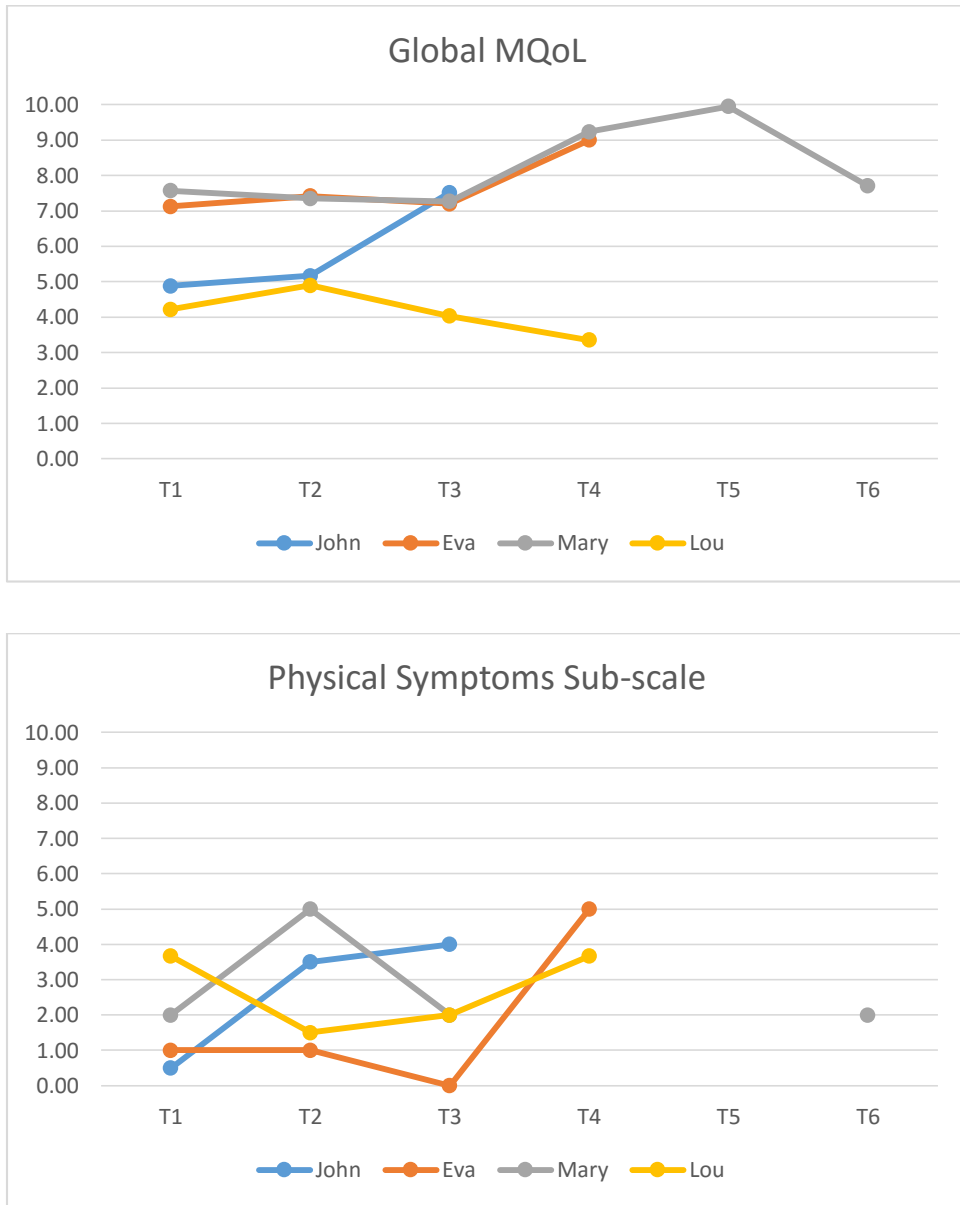
T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

MQoL SIS						
	T1	T2	T3	T4	T5	T6
John	2.00	5.00	8.00			
Eva	3.00	7.00	7.00	10.00		
Mary	8.00	9.00	9.00	9.00	10.00	10.00
Lou	6.00	8.00	4.00	5.00		
n	4.00	4.00	4.00	3.00	1.00	1.00
mean	4.75	7.25	7.00	8.00		
range	2.0 - 8.0	5.0 - 8.0	4.0 - 9.0	5.0 - 10		
Mean	2.75	1.71	2.16	2.65		

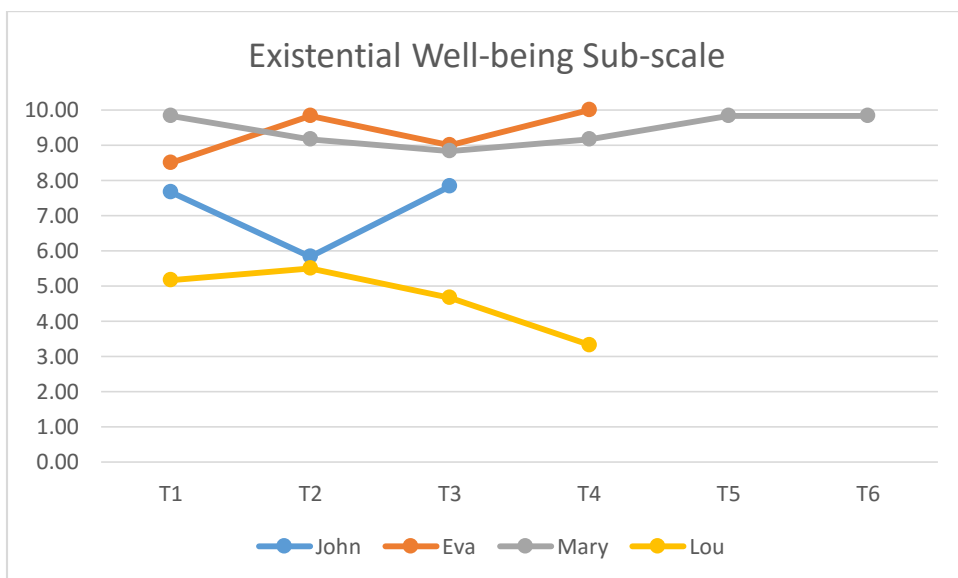
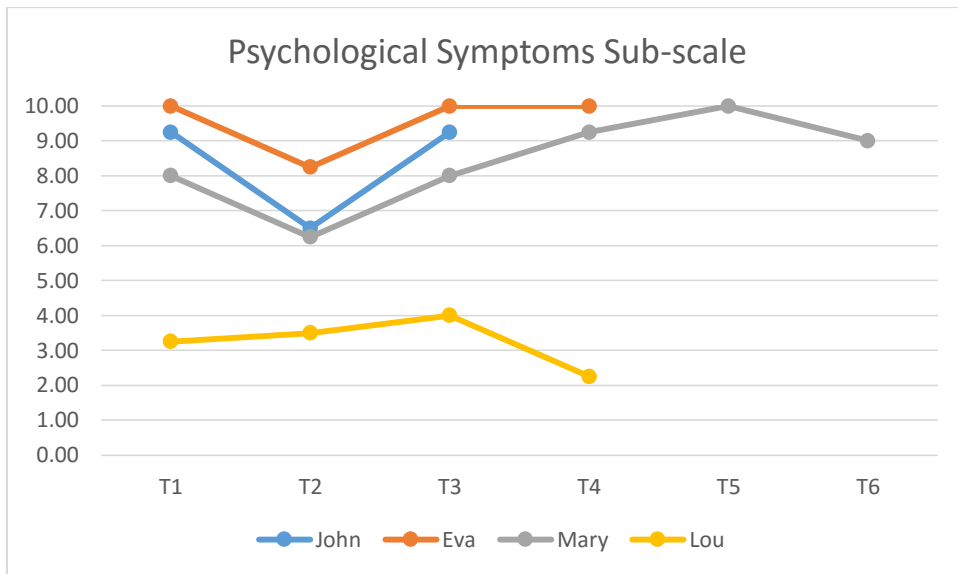
Theoretical range for all sub-scales is 0 – 10. Higher scores indicate higher QoL.

T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

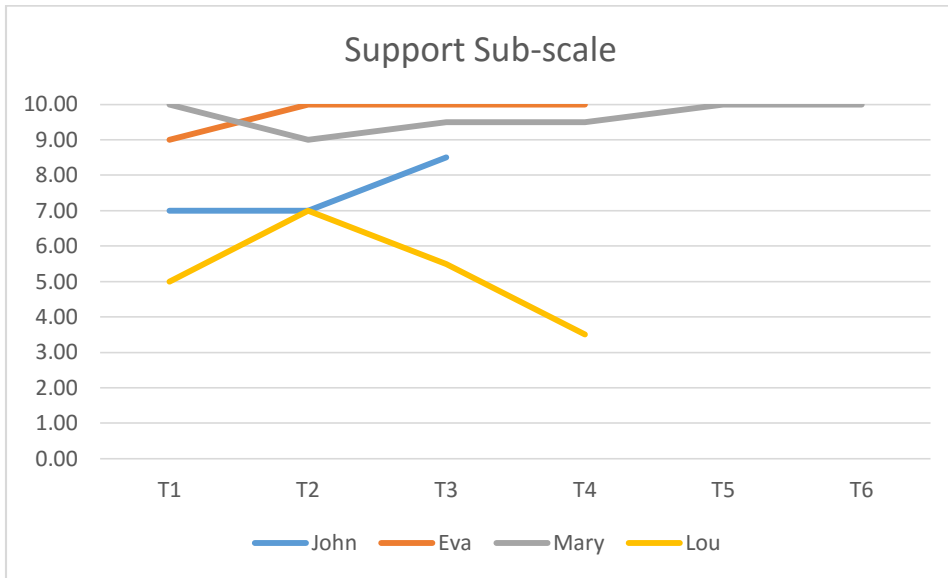
Figure 4.4: QoL Trajectories Across Care Transitions



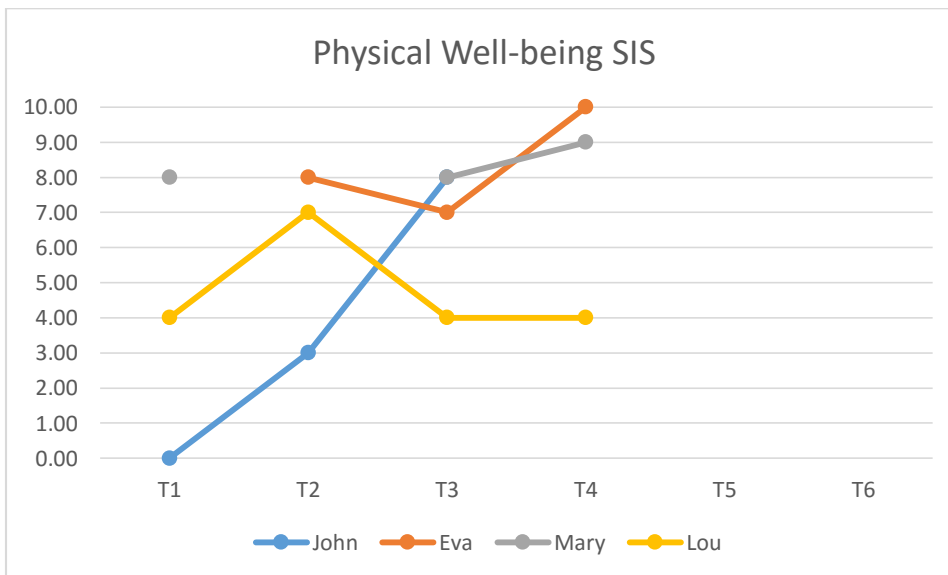
Theoretical range for all sub-scales is 0 – 10. Higher scores indicate higher QoL.
 T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

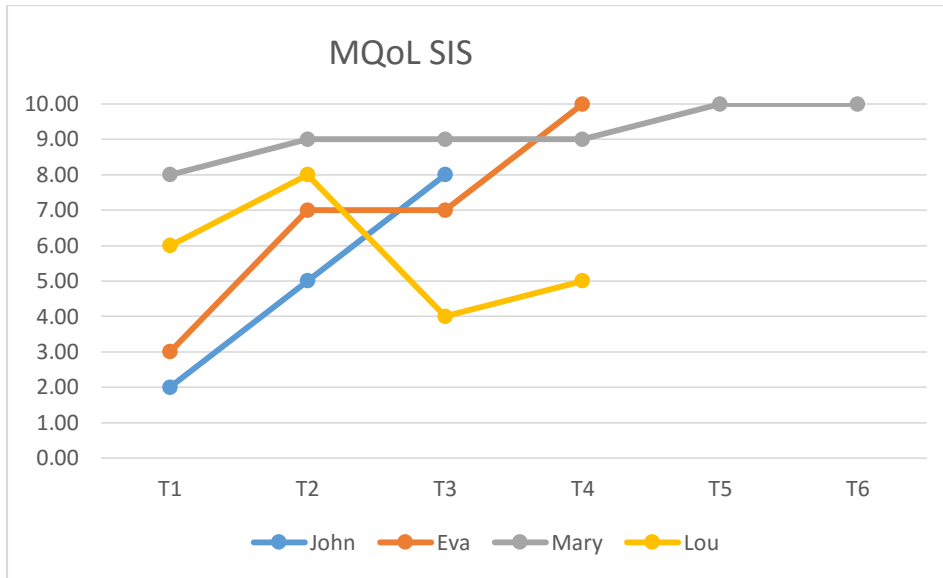


Theoretical range for all sub-scales is 0 – 10. Higher scores indicate higher QoL.
 T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge



Theoretical range for all sub-scales is 0 – 10. Higher scores indicate higher QoL.
 T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge





Theoretical range for all sub-scales is 0 – 10. Higher scores indicate higher QoL.
 T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

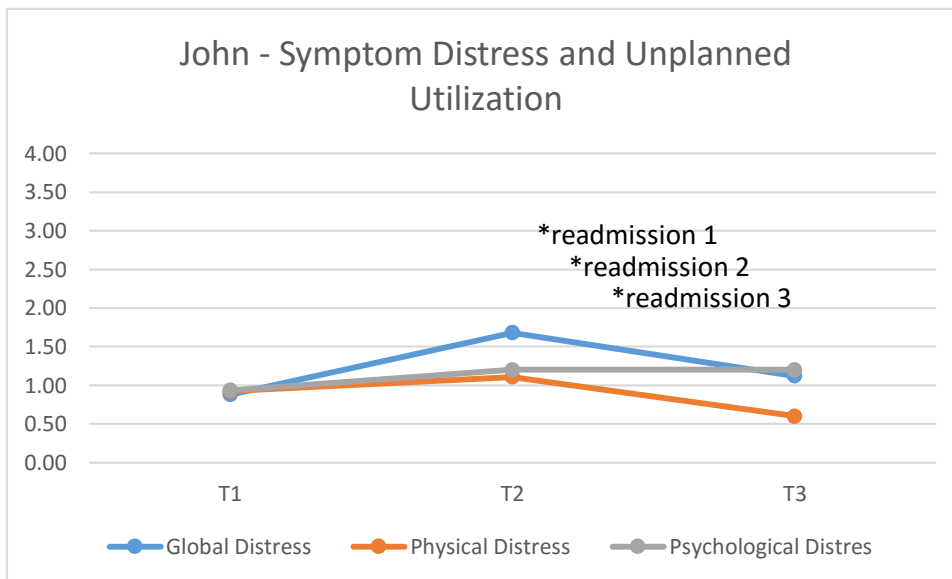
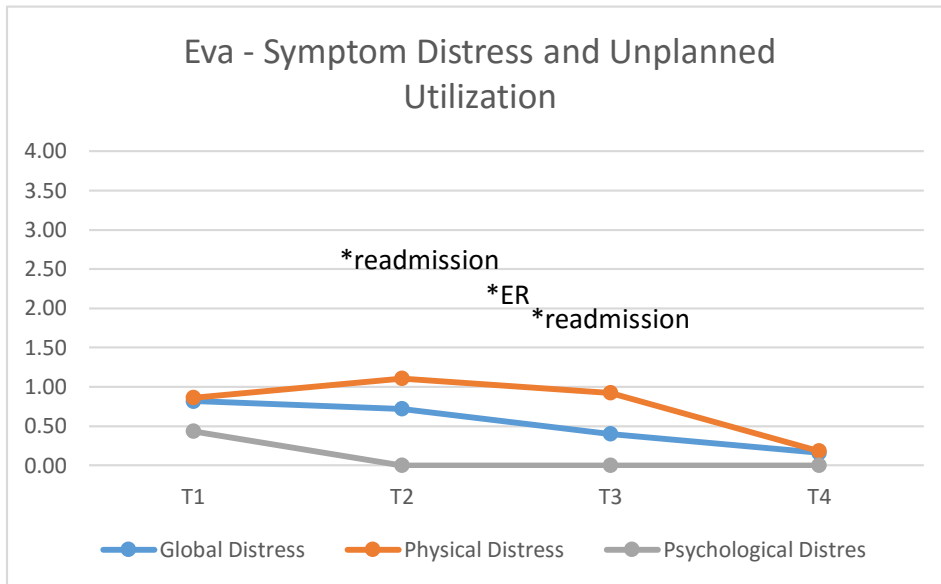
Table 4.12: MQoL Physical Symptoms or Problems Over the Past Two Days

	I1	I2	I3	I4	I5	I6
John	<ul style="list-style-type: none"> • Urinary catheter • [lab values] going back up 	<ul style="list-style-type: none"> • Persistent pain from incision • Stuffed nose 	<ul style="list-style-type: none"> • Edema in legs and feet • Dry skin on feet • [lab values] 			
Mary	<ul style="list-style-type: none"> • Would like to be at home • Anxious 	<ul style="list-style-type: none"> • Anxiety 	<ul style="list-style-type: none"> • Anxiety in evenings 	<ul style="list-style-type: none"> • none 	<ul style="list-style-type: none"> • none 	<ul style="list-style-type: none"> • backache
Eva	<ul style="list-style-type: none"> • Pain on left side of face 	<ul style="list-style-type: none"> • Bell's Palsy, drooping, talking, eating 	<ul style="list-style-type: none"> • Dizzy & swirling, thought would pass out 	<ul style="list-style-type: none"> • Vision – getting better, but not like it should be 		
Lou	<ul style="list-style-type: none"> • Sinusitis • Vision • Lack of strength with doing for myself 	<ul style="list-style-type: none"> • Diarrhea • Vision problems 	<ul style="list-style-type: none"> • Tiredness • Diarrhea • Frustrated 	<ul style="list-style-type: none"> • Weakness • Worry / wondering about heart • DM – low BS 		

Table 4.13: Hospital Readmission Timing and Clinical Necessity

Readmission	Days from initial hospital discharge	Days from most recent hospital discharge	Clinically necessary	Criteria met
1	8	-	Y	Non-operating room invasive procedure
2	18	5	Y	Abnormal VS
3	24	3	Y	ICU admission
4	5	-	Y	ICU admission
5	24	16	Y	WBC count >12
6	84		Y	Non-operating room invasive procedure

Figure 4.5: Symptom Distress Trajectories and Unplanned Healthcare Utilization



Theoretical range for all sub-scales is 0 – 4. Higher scores indicate higher distress.

T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

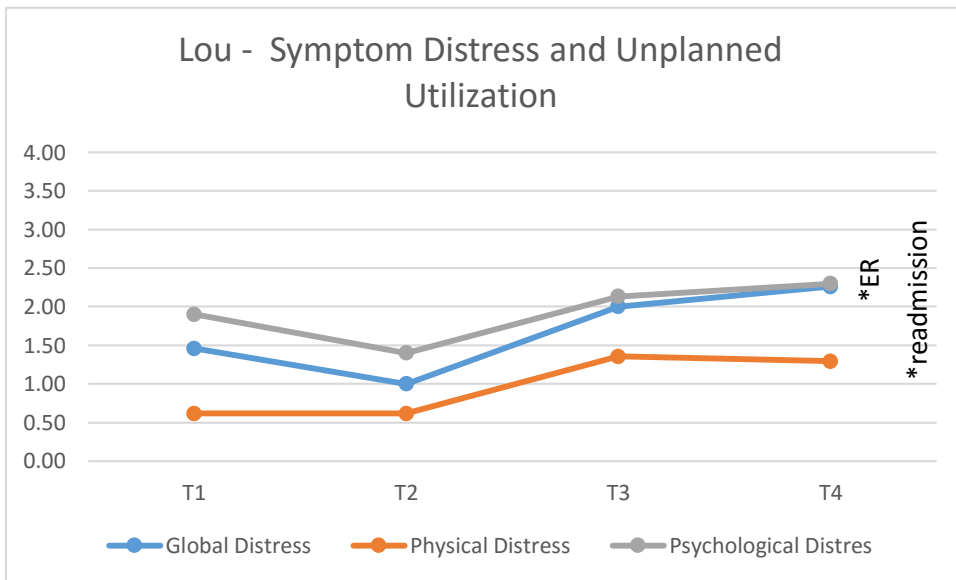
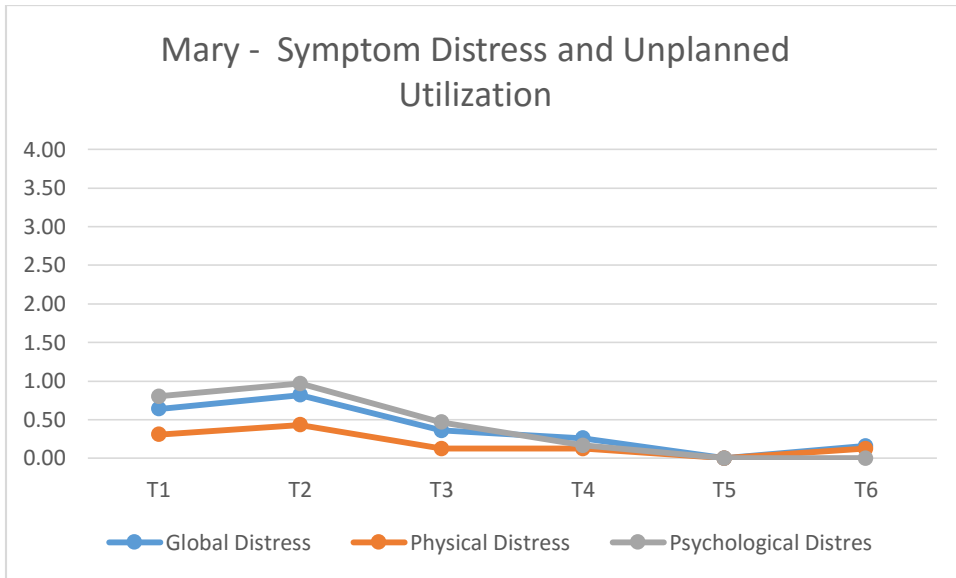
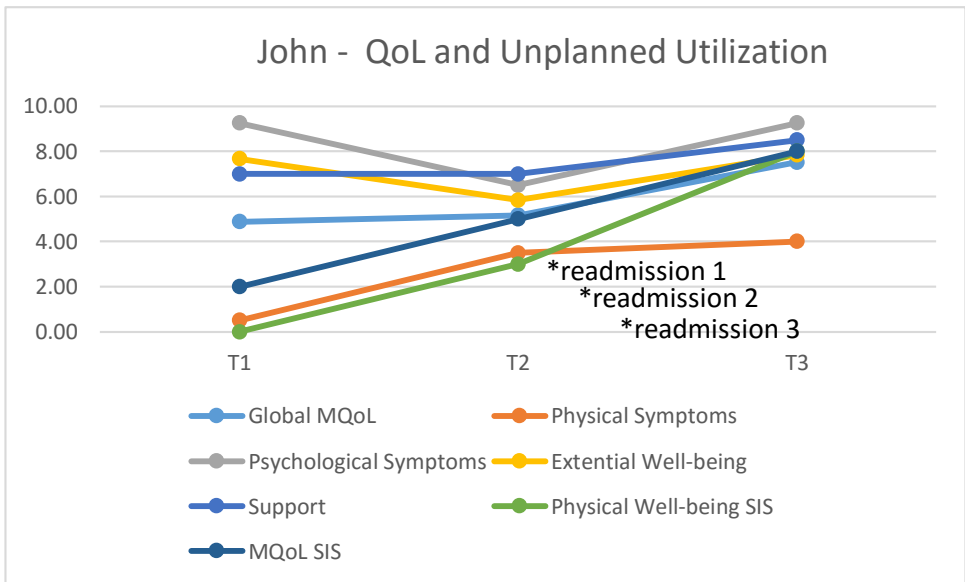
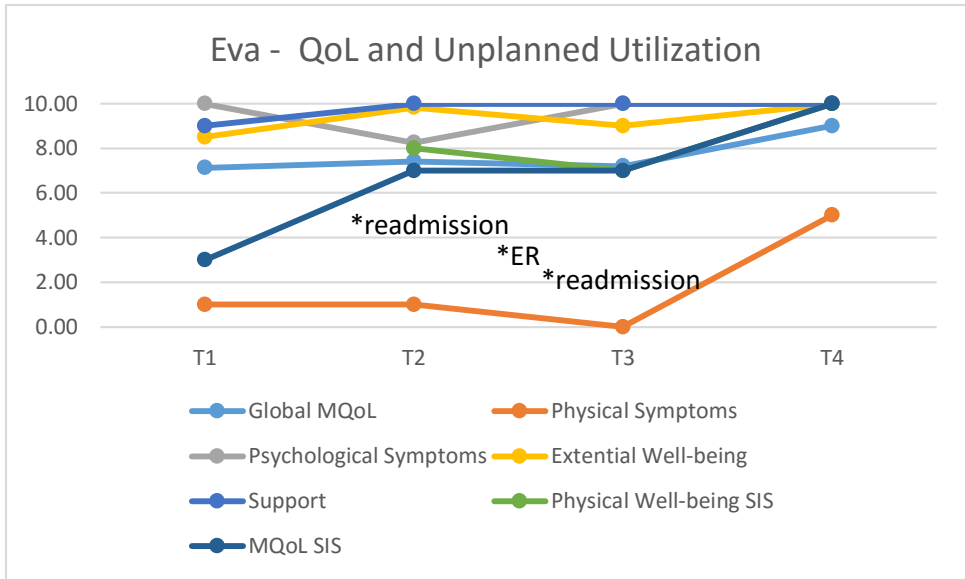
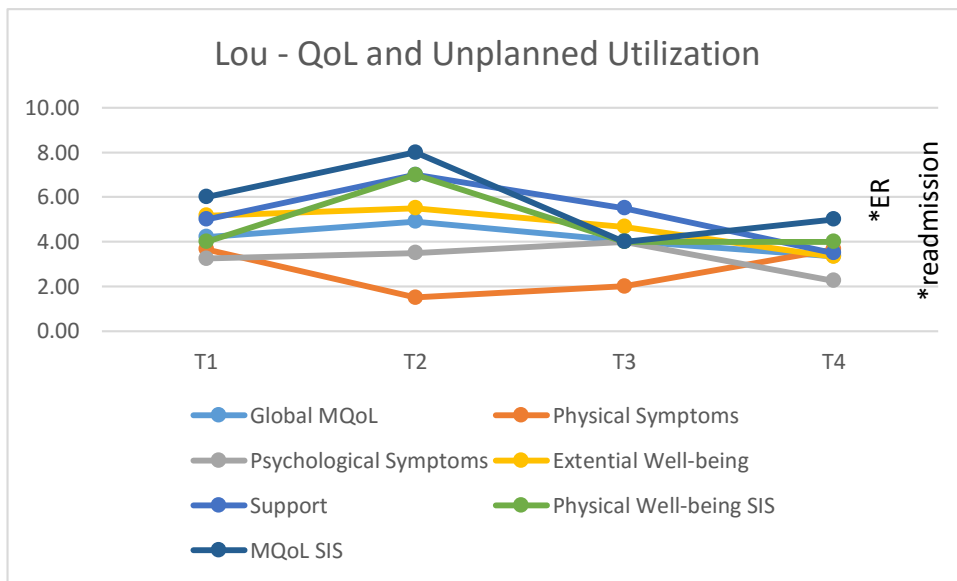
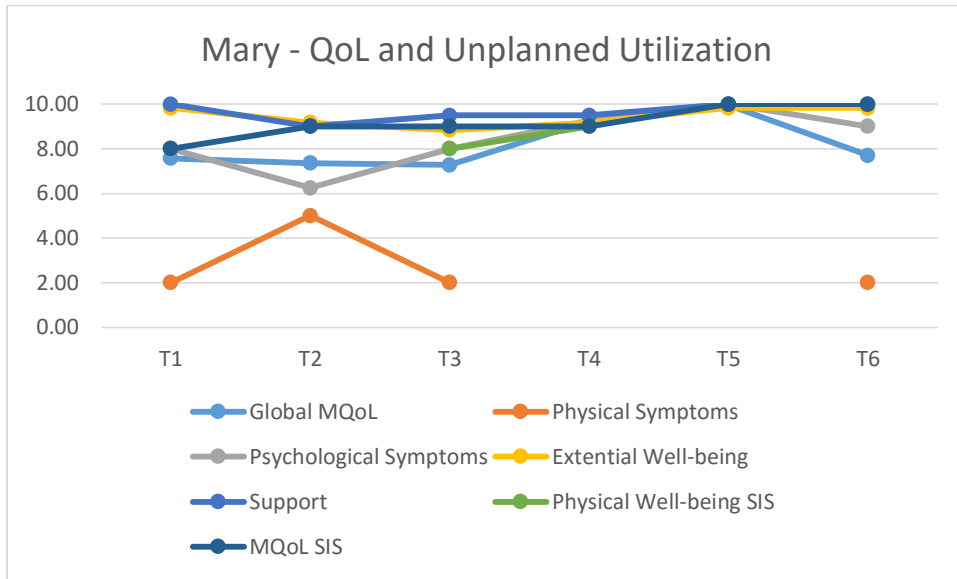


Figure 4.6: QoL Trajectories and Unplanned Healthcare Utilization

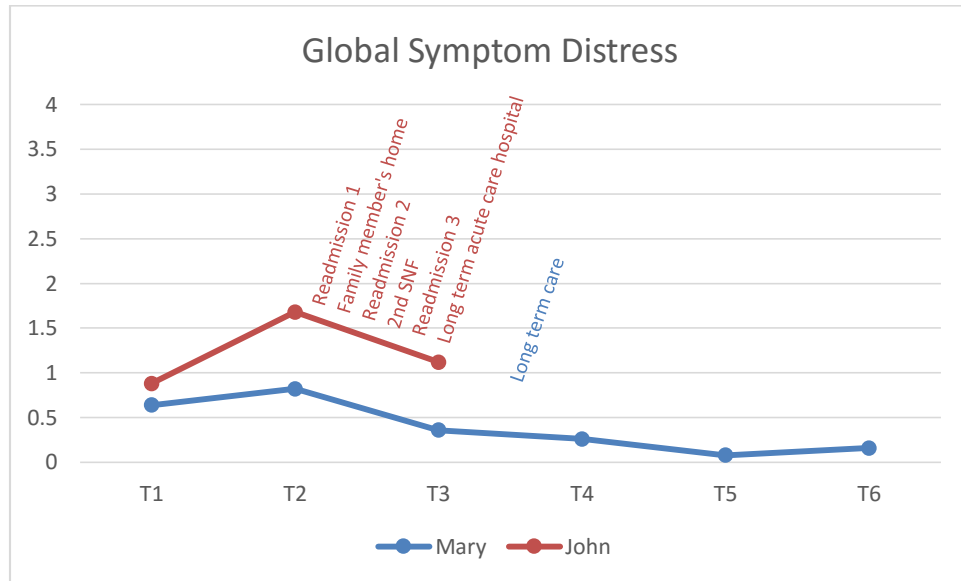


Theoretical range for all sub-scales is 0 – 10. Higher scores indicate higher QoL.
 T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge



Theoretical range for all sub-scales is 0 – 10. Higher scores indicate higher QoL.
 T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

Figure 4.7: Global Distress and Care Transitions



Theoretical range for all sub-scales is 0 – 4. Higher scores indicate higher distress.

T1 = during initial hospitalization, T2 = following transition to NH, final interview = after SNF discharge

Chapter 5: Discussion

I began this dissertation with the statement “Transitions have been defined in multiple ways: as a process and an event; as a patient-phenomena and a systems-requirement.” In this first study to provide a holistic characterization of care transition from hospital to a skilled nursing facility (SNF) and for 120 days following among older adults with advanced chronic illness, it was demonstrated that, in fact, care transitions considered holistically are simultaneously all of these: a process, an event, a patient-phenomena, and a systems-requirement. In characterizing such a complex phenomenon, the perspective one takes is critical to what can be appreciated. Much as the blind men in the poem from Chapter 2, with each perspective of care transition a distinct understanding of its characteristics can be discerned.

Three distinct characterizations of care transition identified within this study all relate to the perspective used to view the phenomenon. First, healthcare provider (HCP) care transition processes are complicated. That is, there are many details to manage, but they configure in patterned ways (Sargut & McGrath, 2011). However, for principals and family caregivers, care transitions and the dynamics within them are quite complex in that there are multiple potentially interacting elements that are both interdependent within an individual care transition and diverse in their understanding of and relationship to the principal and the care transition (Sargut & McGrath, 2011). Second, role fragmentation and lack of feedback starved both individual HCPs and the facilities as a whole of information. Thus, challenging adaptation. Finally, current outcome measures did not provide adequate information to support learning and adaptation in such dynamic situations. I will detail each of these contributions to scientific knowledge below.

Care Transition Processes

Care transitions were complicated HCP-centered processes. The processes contained detailed steps. Multiple disciplines working in distinct roles completed these steps and focused on events that were key to their performance. For example, generating the “list” of nursing homes for consideration and completion of nurse-to-nurse report were each steps within the hospital discharge process for specific hospital-based HCPs. Similar process steps existed within the SNFs. These care transition processes were developed following best practice guidelines and modified for clinical population needs to meet system requirements. As such, focused process-based metrics were central to HCP processes and were considered in the form of rules: give the patient a list of nursing homes; do not offer suggestions or input regarding specific facilities; the patient and / or family must agree with the plan; there must be an adequate hospital stay. Each of these rules guided a portion of the care transition process. Each of these rules responded to a system requirement linked to payment.

In these systems requirement-guided processes, the principal experience was considered. However, there was no venue within the processes for considering the uniqueness of the individual, beyond their clinical plan and social deficits. Questions were asked about preferences, available support, and barriers to a return to home, but the level of consideration was tactical and episodic: nursing home or home with home health care, will durable medical equipment be needed and reimbursable, etc. Broader options and linking of the options to the principal’s life transition was absent unless the principal or family forcefully pushed the life transition into the conversation or managed the life transition independently within the context of the care transition. Both of these approaches were seen within this study.

These complicated processes of care transition occurred within complex systems. I will first use the characteristics described in Chapter 2 to support this affirmation. Within these care transitions there were multiple (learning) agents. In the next section, I will describe the rationale for parentheses around

'learning'. For now, there were multiple agents, both human and non-human within the care transitions within this study: HCPs from multiple disciplines, administrators, principals, family caregivers, regulations, documentation systems, both paper and electronic, among others. These agents were all involved in other situations and events, but all came together to ensure that the principal's care transition occurred.

These multiple agents engaged in dynamic interaction in the course of the care transition. Families modified their Familial Approach to Principal Support and principals, family caregivers and HCPs worked to achieve care for the principal. This dynamic interaction was at various times tactical, closed, or open. In more effective dynamics, the principal needs and Familial Approaches to Principal Support were aligned. Regardless, interaction was dynamic.

This dynamic interaction prompted non-linear results. For example, a single comment regarding oxygen management became the rationale for long term care placement and a principal forcefully demanding that his interests be considered allowed a new approach to his care to emerge. The principal, family caregivers, and HCPs in a single case worked together to self-organize in a new form that more effectively supported the principal through multiple care transitions. There were multiple examples of non-linear results, perhaps less dramatic and certainly less positive, within the data.

While much literature has declared healthcare to be composed of complex adaptive systems since Plsek introduced the concept to the mainstream in 2001 (Plsek), this is the first study to demonstrate complexity so vividly. Further enriching the characterization is the recognition that rather than a single Patient-specific Health System as shown in Figure 1.1, there were multiple Patient-specific Health Systems within each case. Lack of continuity among HCPs across care transitions and inconsistent alignment of Familial Approaches to Principal Support at times culminated in care transitions where the principal was the sole core agent across transitions. However, even in cases where there was an effective stable core, care transitions fundamentally changed the Patient-specific Health System. Level

of care norms and regulatory requirements coupled with the dearth of information that principals and family care givers held when they arrived to new level of care fundamentally changed the Patient-specific Health System at transition.

This description of care transitions as multiple complex systems is consistent with what has been suggested in the literature related to complexity in health care (Anderson et al., 2005; Anderson, et al., 2003; Colon-Emeric et al, 2006; McDaniel & Driebe, 2001; Plsek, 2001). However, conditions did not support consistent or ready adaptation from within the health system within this study. Rather, principals and families adapted to bureaucratic system norms. While the health systems were capable of adaptation, the level of conflict required to prompt system change was too substantial for common occurrence.

Fragmentation and Feedback Loops

Consistent with what has been found previously, HCPs within this study described fragmented processes both within and across facilities in terms of care transition planning and continuity of care (Boockvar & Burack, 2007; Lester, Stefanacci, & Chen, 2009; Reed & Morgan, 1999). Fragmentation within facilities occurred through separation of clinical and care management processes and through assignment of narrow portions of the required steps of care transition to different roles. Discontinuity of HCPs across care transitions further fragmented principal relationships and care. In addition, the dramatic change in practice norms between hospital and SNF, driven by regulatory requirements, also caused fragmentation in care transitions. For the principal with no previous SNF admission, the change in medical and nursing practice patterns created a stark break in their recognition of patterns of care within the SNF as compared to their hospital experience.

Feedback loops across care transitions were also lacking, perhaps contributing to limited system adaptation. Across care transitions, whether from higher levels of care to lower or the opposite, no

information save the occasional anecdote, provided insight as to clinical care or care management performance related to the individual principal prior to transition. Although large survey data was provided to the facilities, these data lacked adequate detail and personalization to provide insight into either patterns in care outcomes or avenues for practice improvement. Although hospital to nursing home research has described communication deficits within processes, these studies did not address the importance of feedback mechanisms in routine care (King et al., 2013; Lester et al., 2009)

This fragmentation and lack of feedback loops limited information flow to and within the Patient-specific Health System as well as the HCP agents within the complex systems. This lack of information impeded individual and facility potential to act as learning agents and challenged the ability of the complex system to adapt to changes in environment or situation. The importance of information flow has been described within studies completed within nursing homes (Anderson et al., 2005; Anderson, et al., 2003; Colon-Emeric et al., 2006; Forbes-Thompson, et al., 2007). However, no literature describing its importance in care transitions has been found.

The HCPs' lack of knowledge regarding other levels of care was also seen both within this study and in the literature (Reed & Morgan, 1999). This lack of knowledge, even among those working in care management roles within the hospital and admission coordinator roles in the SNF, was striking. However, opportunities for formal or informal connection across facility boundaries were not described. Information flow across level of care was starkly limited to individual patients and only until the transition was complete.

Characteristics within the care transition processes and HCPs were, at least in part, explained by this lack of information. Within hospital discharge processes, there was little operational diversity in the care management processes across the two hospitals. HCPs within both facilities described the same steps and used the same rules (regulations) to justify their approaches. In spite of different missions and medical practice models, their care management processes were nearly identical. If the agents within

these systems had adequate information, they would have learned and responded by adapting, creating differences between systems. However, in the absence of information and diversity in the ways that agents process information, there was no potential for adaptation (McDaniel & Driebe, 2001).

Within this study, HCPs did occasionally receive feedback from principals and family caregivers during care transition planning. This feedback ranged from simple statements that the principal or family caregivers preferred a specific level of care to forceful and crass statements of unwillingness to participate. When given feedback *that created adequate conflict*, HCPs did adapt and helped to create new options for principals and family caregivers. However, the norm was principal and caregiver conformity to typical healthcare system care transition patterns.

Outcome Measures

Identified outcome measures were not adequate to reflect the complexity of care transitions from hospital to SNF or the multiple care transitions that followed within this study. As was seen within the mixed methods analysis, discrete measures did not tell the story behind a finding. Without context related to the dynamics, low arcing Global Symptom Distress in the context of multiple readmissions might have caused questioning of the necessity of those readmissions. However, with context (i.e. clinical causes, abrupt life transition, and misaligned dynamic interactions) an entirely different picture emerges. This context-based picture makes clear that narrow outcomes are not adequate measures of value in this complex situation.

Rather, outcomes measures that include consideration of the multiple dynamics of care contexts such as the life transition and dynamic interactions as well as clinical and economic outcomes are necessary to evaluate and incentivize care. Such requests are not unique. Person-centered care includes such suggestions for performance measurement (The American Geriatrics Society Expert Panel on Person-Centered Care, 2015) as do critics of value-based payments (Lynn, McKethan, & Jha, 2015).

These outcomes must also connect the interests and values of the ‘patient’ to the measured results of care. One of the strongest statements in this dissertation was presented in a single sentence declaring that the patient would be referred to as “principal.” In the findings, the patient was working to be more than a patient. And, they were more than patients, they were individuals with rich history and much promise for the future. They were important members of families with roles that they and their families held dear. And, they were not planning for the end of their lives, but the rest of their lives. Such personalization in outcomes measurement is necessary in this population: chronically ill and with advancing disease, without hope for “cure” but also without anticipation of death near term (Lynn, McKethan, & Jha, 2015; The American Geriatrics Society Expert Panel on Person-Centered Care, 2015).

Implications for practice, research, and policy

These findings hold important implications for practice, policy, and research.

Implications for practice.

Acceptance of healthcare systems as complex adaptive systems has been relatively recent. Identification of barriers to system adaptation within this study was striking. However, such findings indicate the need for quick and sure system changes if we are to accomplish such lofty goals as person-centered care. These changes must address fragmentation and lack of feedback loops, inadequate information, and consideration of the ‘patient’ as the principal with a much greater story than the episode of care.

The findings here identified fragmentation as the practice norm. This fragmentation occurred at each facility admission and discharge with new medical and facility-based providers introduced at each. Fragmentation also occurred within both hospital and SNF where care management and clinical care were performed within different HCP roles. Information sharing across these roles was accomplished through formal meetings, but did not include all involved HCPs. Practice changes to improve continuity

of care are needed to support building relationships and knowledge necessary to clinical management of these patients.

Information flow was hampered in part due to this fragmentation of role and relationship. However, there was also limited information available to principals and families as they planned for care transitions. Access to local, patient-focused information about the implications of transitioning to a nursing home for skilled care, in general, and to an individual nursing home, in specific, was severely limited. Principals and family caregivers considered acquaintance accounts of nursing home experiences decades-old as they attempted to make sense of their choices. Improved access to relevant, timely, and practical information is needed. For example, nursing home visits using online means would allow the principal to engage effectively in the decision.

Although HCPs were aware of the situations that created principal life transitions, they did not typically appreciate the meaning of these life transitions for the principal and the family caregivers. Likewise, HCPs often accepted principal status within the hospital as 'typical' for the principal. However, principal and family caregivers noted both acute and chronic (insidious) changes that occurred in close proximity to the initial hospital admission. Lack of HCP awareness of these differences in perception of principal norms formed an additional form of poor information flow – information about the principal and his or her potential.

Increasing information flow and decreasing points of fragmentation offer great potential to improve individual care transition results and to enhance the healthcare facility's potential to effectively adapt to individual principal needs and changing environments.

Implications for research

Findings within the study support recognition of health care as occurring within multiple complex systems. As such, future research should be conducted with consideration of the complex

nature within these systems. For example, inclusion of dynamic interactions and relationships in addition to events will be important to knowledge development. In addition, recognition that there is not a single personal-health system, but multiple is also important to research. Study of such phenomena as person-centered care will require consideration of this multiplicity within care delivery.

The dynamic nature of care provided within these complex systems requires attention. Traditionally research is designed to keep dynamics out of scope and rather to focus narrowly on more quantifiable (or perhaps manageable) variables. Care transitions occur within these dynamic interactions. Therefore, study of care transitions requires consideration of the dynamic interactions between principals, family caregivers, and all involved HCPs.

Outcomes measures within this study did not inform as anticipated. Symptom distress, quality of life, and unplanned utilization did not connect to provide substantial insight into clinical or systems approaches to improving care transitions. Rather, it is clear that for this patient population – those with advanced (multiple) chronic conditions – that no single outcome measure emerged as enlightening across, or even within, cases. Rather than inadequately managed symptom distress prompting readmissions, advancing acute and chronic conditions, not manageable within the lower levels of care, forced readmission. Readmission was clinically necessary and perhaps a clinical reality of advancing chronic illness. New outcomes measures for use within those with multiple chronic conditions are needed.

Implications for policy.

Thorough analysis of Chronic Care Management policies are beyond the scope of this dissertation. However, several clear benefits and concerns are evident. Each principal within the study presented to the emergency room for their initial hospital admission. At this visit, all save one was introduced to a new physician. This one placed a call to her primary care physician who maintained continuity of care.

All others were seen by a new emergency room physician followed by new specialists. The requirements of Chronic Care Management Services billing through CMS requires the establishment of continuous access to care management services (Centers for Medicare & Medicaid Services, 2015). It is anticipated that use of such a service would have improved continuity of care within the emergency room and throughout the hospitalization. At the minimum, it would have increased the potential for the principal to arrive at an emergency room with an established relationship with the primary provider.

Of concern, however, is the large number of medical providers involved in the care of these principals and the dramatic number of care transitions within 30 days of the initial hospital discharge. Time allocation for chronic care management (20 minutes) and the inability to bill for transitional care services in addition to chronic care management in spite of distinct services offered, signal inadequate payment for these services.

Limitations of this research.

Within these four cases, participants had much in common. Participants were largely Caucasian and from a single mid-western city. While family dynamics were variable across cases, all of the principal support systems were family-based. As important, this study focused on a unique population: those hospitalized and aging with advanced chronic illness. These principals, while allowing for a strong description of the complexities of care transition from hospital to SNF, may not be representative of the whole of care transitions from hospital to SNF. Likewise, care transitions from hospital to long term care were not considered within the study. Based on findings here, it is anticipated that hospital to long term care transitions will prove unique, as well.

Although care was taken to include multiple perspectives within this study, case boundaries and study personnel excluded some perspectives. Multiple healthcare disciplines participated in the study. However, study personnel were all nurses. In addition, communication and medical records housed

outside of participating facilities were outside the scope of the study. Therefore, only a fraction of non-facility-based practitioner medical records were available during SNF admissions.

Conclusion.

Despite these limitations, this study provides important insights into care transitions from hospital to SNF. These care transitions occurred within two contexts: the facilities' organizational context and the principals' ongoing life transitions. The care transitions were complicated HCP-centered processes. These time-bounded processes were fragmented and lacked feedback mechanisms. Defined outcome measures did not adequately reflect the complexity.

Dynamic interactions between principals, family caregivers, and HCPs necessary to complete care transitions occurred within multiple complex systems. These dynamic interactions were affected by alignment of the familial approach to principal support with the principals' needs and the availability of a stable core.

Implications for practice relate to the complexity within care transitions. Limited information flow due to fragmented processes and lack of feedback loops hampered learning and adaptation both within individual cases and across facilities. Design of future research must include consideration of complex systems. Inclusion of not only processes and endpoints, but also relationships and dynamic interactions will be needed.

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Appendix A: Qualitative Protocols

A1: Health Care Provider Interview Guide

A2: Patient Interview Guide

A3: Caregiver Interview Guide

A1: Health Care Provider Interview Guide

**HOSPITALIZED OLDER ADULTS' CARE TRANSITION: THEMES,
SYMPTOMS, QoL AND UTILIZATION**

HEALTH CARE PROVIDER INTERVIEW GUIDE

**Carol Geary, RN, MBA
Principal Investigator**

**School of Nursing
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A1: Health Care Provider Interview Guide

HOSPITALIZED OLDER ADULTS' CARE TRANSITION: THEMES, SYMPTOMS, QoL AND

UTILIZATION

HEALTH CARE PROVIDER INTERVIEW GUIDE

I am here to learn about care transitions in this facility. I am interested in your perspective on transitions from the time a patient is identified as a potential discharge to NH until they are either admitted as a resident or transitioned to another situation after completing skilled nursing care.

Additional probes:

- Discharge / admission process
- Strengths? Weaknesses?
- What does "success" look like? "failure"?
- Transfer decision process / parameters/criteria
- Agents involved

- Are there other processes, issues or dynamics that I should be aware of in transitions either within your facility or between the two facilities?

- For NHs, probe other transitions: home, LTC, etc.

During this interview, I will also collect copies of relevant policies/procedures for each of the facilities.

A2: Patient Interview Guide

Study # _____

Date (T0) _____

Care Transitions: A Mixed Methods Study Using a Complexity

Science Lens

Patient Interview Guide

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IRB #358-13-EP Care Transitions: A Mixed Methods Study Using a Complexity Science Lens
Funded by NINR of the National Institutes of Health under award number 1F31NR013596-01A1.

Inpatient Interview

PATIENT

Introduction

Script for the interviewer:

First, let me thank you for agreeing to participate in this study. I know that you are not feeling well right now. If at any point you would like to take a break or have me come back at a later time, please let me know and I will be happy to do so.

The experiences that you share with me will help nurses and other health care professionals better understand what it is like to move from a hospital to **skilled nursing or rehab** care in a nursing home. I appreciate very much your taking the time to participate in this interview and answer my questions.

Let me begin by giving you an idea of where we are going in these interviews. First, I want to explain that I define transition broadly. It is more than the move from here to the NH. It includes anything that you believe is important to your health and well-being.

This interview has two parts. First, I would like to hear about your perspective of transitioning from the hospital to the nursing home. I would like to begin with your experiences here in the hospital, learn about the decision to move into a NH for **skilled nursing or rehab** and your expectations for the NH.

In the second part of the interview, we will complete 2 surveys together. The first asks about symptoms that you may be having. A symptom is a feeling (like pain or headache) or an experience (like losing hair or a fall). I am interested in knowing what symptoms you are having and to what degree those symptoms are bothering you. Even if a symptom isn't bothering you, I would like to know that you are experiencing it.

The last survey will ask about how your life is right now. This survey asks you to use a scale (0 to 10, for example) to describe how life is for you now. On each of these scales, there is no right or wrong answer only a description of your experiences.

Before we begin, do you have any questions about the interview?

Part One: Hospital experiences

Interview:

Let's go back to the beginning of your hospitalization. What brought you to the hospital and how did you come to the decision to go to **the NH**?

The goal here is a story. No specifics / dates. Only interrupt for clarification, not details. If the patient gets off subject, use directive interviewing techniques to get back to the subject. If the patient does not communicate in narrative form, then use more specific probes:

What brought you to the hospital?

What has your experience been here?

Who do you rely on for help while you are here? (family, friends, etc.)

How did you come to the decision to go to a NH? (*aiming for process and contributors*)

How did you choose **the NH**?

Next, get the patient's response to the decision:

What you think and feel about going to **the NH**?

Specific probes:

What are your concerns or fears about going to **the NH**?

What are your goals while you are at **the NH**?

What are the things that give you joy? How will those things be in **the NH**?

Surveys:

During the second part of our interview today, I would like to ask you to fill out 2 surveys.

This usually takes about 15 – 20 minutes. Would you like to take a break before we do this?

For this part of the interview, I will place the page in front of you and read them with you, if you like. If you have any questions about what a question means or how to

complete it, do not hesitate to ask. You may chose whether you would like for me to write the answers or whether you prefer to.

Do you have any questions about this part of the interview?

McGILL QUALITY OF LIFE QUESTIONNAIRE

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

- **If you are not even a little bit hungry, you would circle 0.**
- **If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.**
- **If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.**
- **If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.**
- **If you are extremely hungry, you would circle 10.**

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 excellent

PART B: Physical Symptoms or Physical Problems

- (1) For the questions in Part "B", please list the PHYSICAL SYMPTOMS OR PROBLEMS which have been the biggest problem for you over the past two (2) days. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shortness of breath, lack of appetite, sweating, immobility. Feel free to refer to others if necessary)
- (2) Circle the number which best shows how big a problem each one has been for you
OVER THE PAST TWO (2) DAYS.
- (3) If, over the past two (2) days, you had NO physical symptoms or problems, or only one or two, answer for each of the ones you have had and write "none" for the extra questions in Part B, then continue with Part C.

1. Over the past two (2) days, one troublesome symptom has been: _____

(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous
problem

2. Over the past two (2) days, another troublesome symptom has been: _____

(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous
problem

3. Over the past two (2) days, a third troublesome symptom has been: _____

(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous
problem

4. Over the past two (2) days I have felt:

physically terrible 0 1 2 3 4 5 6 7 8 9 10 physically well

PART C												
Please choose the number which best describes your feelings and thoughts OVER THE PAST TWO (2) DAYS.												
5. Over the past two (2) days, I have been depressed:												
not at all	0	1	2	3	4	5	6	7	8	9	10	extremely
6. Over the past two (2) days, I have been nervous or worried:												
not at all	0	1	2	3	4	5	6	7	8	9	10	extremely
7. Over the past two (2) days, how much of the time did you feel sad?												
never	0	1	2	3	4	5	6	7	8	9	10	always
8. Over the past two (2) days, when I thought of the future, I was:												
not afraid	0	1	2	3	4	5	6	7	8	9	10	terrified
9. Over the past two (2) days, my life has been:												
utterly meaningless and without purpose	0	1	2	3	4	5	6	7	8	9	10	very purposeful and meaningful
10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:												
made no progress whatsoever	0	1	2	3	4	5	6	7	8	9	10	progressed to complete fulfillment
11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:												
completely worthless	0	1	2	3	4	5	6	7	8	9	10	very worthwhile

12. Over the past two (2) days, I have felt that I have:

no control over my life 0 1 2 3 4 5 6 7 8 9 10 complete control over my life

13. Over the past two (2) days, I felt good about myself as a person.

completely disagree 0 1 2 3 4 5 6 7 8 9 10 completely agree

14. To me, the past two (2) days were:

a burden 0 1 2 3 4 5 6 7 8 9 10 a gift

15. Over the past two (2) days, the world has been:

an impersonal unfeeling place 0 1 2 3 4 5 6 7 8 9 10 caring and responsive to my needs

16. Over the past two (2) days, I have felt supported:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

Patient's Name _____ Date ___/___/___ ID # ___

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

- I. **INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						

Patient's Name _____ Date ___/___/___ ID# _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. INSTRUCTIONS: Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Hair loss						
Constipation						
Swelling of arms or legs						
“I don’t look like myself”						
If you had any other symptoms during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you.						
1.						
2.						

II. Below are other commonly listed symptoms. Please indicate if you have had the symptom **DURING THE PAST WEEK**, and if so, how **OFTEN** it occurred.

Check <u>all</u> the symptoms you have had during the PAST WEEK	→→ IF YES, How OFTEN did it occur?				
	Yes [✓]	Rarely [1]	Occasionally [2]	Frequently [3]	Almost Constantly [4]
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

Thank you, again, for taking the time to talk with me.

From here, I will check in to see how you are each day until you go to ***the NH***. A day or two after you arrive there, I will ask to sit down with you again for a discussion like this one.

Do you have any questions?

SNF Admission Interview PATIENT

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences in transitioning from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and that this is difficult while you are ill. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This will help us to improve care in the future.

My questions this time are very similar to those that I asked in the hospital. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since we last spoke in the hospital. After we talk for a while, I will ask you to complete the same 2 surveys that you completed in the hospital. As I said before, your answers may not be the same as during the hospital. Don't feel that you have to remember how you answered (or even consider how you answered) in the hospital. Just answer the question as you feel now.

Before we begin, do you have any questions about the interview?

Ok, now let's begin. Last time we talked about..... (summarize briefly). Starting then and coming up to today, what has happened?

How have your thoughts and expectations of **the NH** changed since arriving?

Specific probes:

When we spoke last, you described being concerned or fearful of.... (summarize). How has this been since you arrived?

You spoke of your goals(summarize) how have they changed or stayed the same?

You described the things that give you joy....(summarize). Have you found those things here?

Is there anything else that I should have asked about the transition from hospital to NH?

Surveys:

During the second part of our interview today, I would like to ask you to fill out 2 surveys.

This usually takes about 15 – 20 minutes. Would you like to take a break before we do this?

For this part of the interview, I will place the page in front of you and read them with you, if you like. If you have any questions about what a question means or how to complete it, do not hesitate to ask. You may chose whether you would like for me to write the answers or whether you prefer to.

Do you have any questions about this part of the interview?

McGILL QUALITY OF LIFE QUESTIONNAIRE

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

- **If you are not even a little bit hungry, you would circle 0.**
- **If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.**
- **If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.**
- **If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.**
- **If you are extremely hungry, you would circle 10.**

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 excellent

12. Over the past two (2) days, I have felt that I have:

no control 0 1 2 3 4 5 6 7 8 9 10 complete
over my control over
life my life

13. Over the past two (2) days, I felt good about myself as a person.

completely 0 1 2 3 4 5 6 7 8 9 10 completely
disagree agree

14. To me, the past two (2) days were:

a burden 0 1 2 3 4 5 6 7 8 9 10 a gift

15. Over the past two (2) days, the world has been:

an 0 1 2 3 4 5 6 7 8 9 10 caring and
impersonal responsive to
unfeeling place my needs

16. Over the past two (2) days, I have felt supported:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

- I. **INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some- what [2]	Quite a Bit [3]	Very Much [4]
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. INSTRUCTIONS: Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Hair loss						
Constipation						
Swelling of arms or legs						
"I don't look like myself"						
If you had any other symptoms during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you.						
1.						
2.						

II. Below are other commonly listed symptoms. Please indicate if you have had the symptom **DURING THE PAST WEEK**, and if so, how **OFTEN** it occurred.

Check <u>all</u> the symptoms you have had during the PAST WEEK	→→ IF YES, How OFTEN did it occur?				
	Yes [✓]	Rarely [1]	Occasionally [2]	Frequently [3]	Almost Constantly [4]
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

Thank you, again, for taking the time to talk with me.

From here, I will check in to see how you are a couple of times each week. There will not be anything formal again for about 4 weeks or until you leave ***SNF or rehab care***.

Do you have any questions?

Day 30 Interview PATIENT

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences in transitioning from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and I appreciate your taking the time to talk with me. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This will help us to improve care in the future.

My questions this time are very similar to those that I asked in the hospital and when you first arrived here. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since you first arrived here. After we talk for a while, I will ask you to complete the same 2 surveys that you completed before. As I said before, your answers may not be the same as during the hospital. Don't feel that you have to remember how you answered (or even consider how you answered) before. Just answer the question as you feel now.

Before we begin, do you have any questions for me?

Ok, now let's begin. Last time we talked about..... (summarize briefly). Starting then and coming up to today, what has happened?

How have your thoughts and expectations of **the NH** changed since arriving?

Specific probes:

When we spoke last, you described being concerned or fearful of.... (summarize). How has this been since you arrived?

You spoke of your goals(summarize) how have they changed or stayed the same?

You described the things that give you joy....(summarize). Have you found those things here?

Surveys:

During the second part of our interview today, I would like to ask you to fill out 2 surveys.

This usually takes about 15 – 20 minutes. Would you like to take a break before we do this?

For this part of the interview, I will place the page in front of you and read them with you, if you like. If you have any questions about what a question means or how to complete it, do not hesitate to ask. You may chose whether you would like for me to write the answers or whether you prefer to.

Do you have any questions about this part of the interview?

MCGILL QUALITY OF LIFE QUESTIONNAIRE

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 excellent

12. Over the past two (2) days, I have felt that I have:

no control over my life	0	1	2	3	4	5	6	7	8	9	10	complete control over my life
-------------------------------	---	---	---	---	---	---	---	---	---	---	----	-------------------------------------

13. Over the past two (2) days, I felt good about myself as a person.

completely disagree	0	1	2	3	4	5	6	7	8	9	10	completely agree
------------------------	---	---	---	---	---	---	---	---	---	---	----	---------------------

14. To me, the past two (2) days were:

a burden	0	1	2	3	4	5	6	7	8	9	10	a gift
----------	---	---	---	---	---	---	---	---	---	---	----	--------

15. Over the past two (2) days, the world has been:

an impersonal unfeeling place	0	1	2	3	4	5	6	7	8	9	10	caring and responsive to my needs
-------------------------------------	---	---	---	---	---	---	---	---	---	---	----	---

16. Over the past two (2) days, I have felt supported:

not at all	0	1	2	3	4	5	6	7	8	9	10	completely
------------	---	---	---	---	---	---	---	---	---	---	----	------------

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

- I. **INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some- what [2]	Quite a Bit [3]	Very Much [4]
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. INSTRUCTIONS: Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Hair loss						
Constipation						
Swelling of arms or legs						
“I don’t look like myself”						
If you had any other symptoms during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you.						
1.						
2.						

II. Below are other commonly listed symptoms. Please indicate if you have had the symptom **DURING THE PAST WEEK**, and if so, how **OFTEN** it occurred.

Check <u>all</u> the symptoms you have had during the PAST WEEK	→→ IF YES, How OFTEN did it occur?				
	Yes [✓]	Rarely [1]	Occasionally [2]	Frequently [3]	Almost Constantly [4]
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

Thank you, again, for taking the time to talk with me.

From here, I will check in to see how you are a couple of times each week. There will not be anything formal again for about 4 weeks.

Do you have any questions?

Day 60 Interview PATIENT

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences in transitioning from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and I appreciate your taking the time to talk with me. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This will help us to improve care in the future.

My questions this time are very similar to those that I asked when we spoke previously. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since you first arrived here. After we talk for a while, I will ask you to complete the same 2 surveys that you completed before. As I said before, your answers may not be the same as before. Don't feel that you have to remember how you answered (or even consider how you answered) before. Just answer the question as you feel now.

Before we begin, do you have any questions for me?

Ok, now let's begin. Last time we talked about..... (summarize briefly). Starting then and coming up to today, what has happened?

How have your thoughts and expectations of **the NH** changed since arriving?

Specific probes:

When we spoke last, you described being concerned or fearful of.... (summarize). How has this been since you arrived?

You spoke of your goals(summarize) how have they changed or stayed the same?

You described the things that give you joy....(summarize). Have you found those things here?

Surveys:

During the second part of our interview today, I would like to ask you to fill out 2 surveys.

This usually takes about 15 – 20 minutes. Would you like to take a break before we do this?

For this part of the interview, I will place the page in front of you and read them with you, if you like. If you have any questions about what a question means or how to complete it, do not hesitate to ask. You may chose whether you would like for me to write the answers or whether you prefer to.

Do you have any questions about this part of the interview?

MCGILL QUALITY OF LIFE QUESTIONNAIRE

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 excellent

PART C	Please choose the number which best describes your feelings and thoughts OVER THE PAST TWO (2) DAYS.											
5. Over the past two (2) days, I have been depressed:												
not at all	0	1	2	3	4	5	6	7	8	9	10	extremely
6. Over the past two (2) days, I have been nervous or worried:												
not at all	0	1	2	3	4	5	6	7	8	9	10	extremely
7. Over the past two (2) days, how much of the time did you feel sad?												
never	0	1	2	3	4	5	6	7	8	9	10	always
8. Over the past two (2) days, when I thought of the future, I was:												
not afraid	0	1	2	3	4	5	6	7	8	9	10	terrified
9. Over the past two (2) days, my life has been:												
utterly meaningless and without purpose	0	1	2	3	4	5	6	7	8	9	10	very purposeful and meaningful
10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:												
made no progress whatsoever	0	1	2	3	4	5	6	7	8	9	10	progressed to complete fulfillment
11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:												
completely worthless	0	1	2	3	4	5	6	7	8	9	10	very worthwhile

12. Over the past two (2) days, I have felt that I have:

no control 0 1 2 3 4 5 6 7 8 9 10 complete
over my control
life over
my life

13. Over the past two (2) days, I felt good about myself as a person.

completely 0 1 2 3 4 5 6 7 8 9 10 completely
disagree disagree agree

14. To me, the past two (2) days were:

a burden 0 1 2 3 4 5 6 7 8 9 10 a gift

15. Over the past two (2) days, the world has been:

an 0 1 2 3 4 5 6 7 8 9 10 caring and
impersonal impersonal responsive to
unfeeling place my needs

16. Over the past two (2) days, I have felt supported:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

- I. **INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some- what [2]	Quite a Bit [3]	Very Much [4]
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. INSTRUCTIONS: Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <i>all</i> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Hair loss						
Constipation						
Swelling of arms or legs						
"I don't look like myself"						
If you had <u>any other symptoms</u> during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you.						
1.						
2.						

II. Below are other commonly listed symptoms. Please indicate if you have had the symptom **DURING THE PAST WEEK**, and if so, how **OFTEN** it occurred.

Check <i>all</i> the symptoms you have had during the PAST WEEK	→→ IF YES, How OFTEN did it occur?				
	Yes [✓]	Rarely [1]	Occasionally [2]	Frequently [3]	Almost Constantly [4]
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

Thank you, again, for taking the time to talk with me.

From here, I will check in to see how you are a couple of times each week. There will not be anything formal again for about 4 weeks or until you leave ***SNF or rehab***.

Do you have any questions?

Day 90 Interview PATIENT

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences in transitioning from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and I appreciate your taking the time to talk with me. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This will help us to improve care in the future.

My questions this time are very similar to those that I asked when we spoke previously. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since you first arrived here. After we talk for a while, I will ask you to complete the same 2 surveys that you completed before. As I said before, your answers may not be the same as before. Don't feel that you have to remember how you answered (or even consider how you answered) before. Just answer the question as you feel now.

Before we begin, do you have any questions for me?

Ok, now let's begin. Last time we talked about..... (summarize briefly). Starting then and coming up to today, what has happened?

How have your thoughts and expectations of **the NH** changed since arriving?

Specific probes:

When we spoke last, you described being concerned or fearful of.... (summarize). How has this been since you arrived?

You spoke of your goals(summarize) how have they changed or stayed the same?

You described the things that give you joy....(summarize). Have you found those things here?

Is there anything else that I should have asked you?

Surveys:

During the second part of our interview today, I would like to ask you to fill out 2 surveys.

This usually takes about 15 – 20 minutes. Would you like to take a break before we do this?

For this part of the interview, I will place the page in front of you and read them with you, if you like. If you have any questions about what a question means or how to complete it, do not hesitate to ask. You may choose whether you would like for me to write the answers or whether you prefer to.

Do you have any questions about this part of the interview?

MCGILL QUALITY OF LIFE QUESTIONNAIRE

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 excellent

PART C		Please choose the number which best describes your feelings and thoughts OVER THE PAST TWO (2) DAYS.										
5. Over the past two (2) days, I have been depressed:												
not at all	0	1	2	3	4	5	6	7	8	9	10	extremely
6. Over the past two (2) days, I have been nervous or worried:												
not at all	0	1	2	3	4	5	6	7	8	9	10	extremely
7. Over the past two (2) days, how much of the time did you feel sad?												
never	0	1	2	3	4	5	6	7	8	9	10	always
8. Over the past two (2) days, when I thought of the future, I was:												
not afraid	0	1	2	3	4	5	6	7	8	9	10	terrified
9. Over the past two (2) days, my life has been:												
utterly meaningless and without purpose	0	1	2	3	4	5	6	7	8	9	10	very purposeful and meaningful
10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:												
made no progress whatsoever	0	1	2	3	4	5	6	7	8	9	10	progressed to complete fulfillment
11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:												
completely worthless	0	1	2	3	4	5	6	7	8	9	10	very worthwhile

12. Over the past two (2) days, I have felt that I have:

no control over my life 0 1 2 3 4 5 6 7 8 9 10 complete control over my life

13. Over the past two (2) days, I felt good about myself as a person.

completely disagree 0 1 2 3 4 5 6 7 8 9 10 completely agree

14. To me, the past two (2) days were:

a burden 0 1 2 3 4 5 6 7 8 9 10 a gift

15. Over the past two (2) days, the world has been:

an impersonal unfeeling place 0 1 2 3 4 5 6 7 8 9 10 caring and responsive to my needs

16. Over the past two (2) days, I have felt supported:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

- I. **INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some- what [2]	Quite a Bit [3]	Very Much [4]
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. INSTRUCTIONS: Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Hair loss						
Constipation						
Swelling of arms or legs						
"I don't look like myself"						
If you had <u>any other symptoms</u> during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you.						
1.						
2.						

II. Below are other commonly listed symptoms. Please indicate if you have had the symptom **DURING THE PAST WEEK**, and if so, how **OFTEN** it occurred.

Check <u>all</u> the symptoms you have had during the PAST WEEK	→→ IF YES, How OFTEN did it occur?				
	Yes [✓]	Rarely [1]	Occasionally [2]	Frequently [3]	Almost Constantly [4]
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

Thank you, again, for taking the time to talk with me.

From here, I will check in to see how you are a couple of times each week. There will not be anything formal again for about 4 weeks or until you leave ***SNF or rehab***.

Do you have any questions?

Final (Day 120) Interview PATIENT

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences in transitioning from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and I appreciate your taking the time to talk with me. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This will help us to improve care in the future.

My questions this time are very similar to those that I asked when we spoke previously. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since we last spoke. After we talk for a while, I will ask you to complete the same 2 surveys that you completed before. Your answers may not be the same as before. Don't feel that you have to remember how you answered (or even consider how you answered) before. Just answer the question as you feel now.

Before we begin, do you have any questions for me?

Ok, now let's begin. Last time we talked about.... (summarize briefly). Since then, much has changed. You are now **acknowledge residence**. Tell me about your experiences since our list conversation.

The goal here is a story. Probes should be for clarification rather than details. If the patient gets off subject, use directive interviewing techniques to get back to the subject. If the patient does not communicate in narrative form, then use more specific probes:

How did you come to the decision to come here?

How was planning to come here? (decision, support people, glitches, etc)

How have things been since you arrived here? (support, successes, problems, etc)

How have your thoughts of **the NH** changed since **the move**?

Specific probes:

In the hospital, you described being concerned or fearful of.... (summarize). After **nearly 3 mos**, how has your perception of this changed?

You spoke of your goals(summarize how they changed over time) what is your perception of those goals now?

You described the things that give you joy....(summarize). Have you found those things **here**

Is there anything that I have not asked you about your experiences that you consider important for me to understand?

Is there anything else that I should have asked you?

Surveys:

During the second part of our interview today, I would like to ask you to fill out 2 surveys.

This usually takes about 15 – 20 minutes. Would you like to take a break before we do this?

For this part of the interview, I will place the page in front of you and read them with you, if you like. If you have any questions about what a question means or how to complete it, do not hesitate to ask. You may choose whether you would like for me to write the answers or whether you prefer to.

Do you have any questions about this part of the interview?

MCGILL QUALITY OF LIFE QUESTIONNAIRE

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

- **If you are not even a little bit hungry, you would circle 0.**
- **If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.**
- **If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.**
- **If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.**
- **If you are extremely hungry, you would circle 10.**

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 excellent

12. Over the past two (2) days, I have felt that I have:

no control 0 1 2 3 4 5 6 7 8 9 10 complete
over my control over
life my life

13. Over the past two (2) days, I felt good about myself as a person.

completely 0 1 2 3 4 5 6 7 8 9 10 completely
disagree agree

14. To me, the past two (2) days were:

a burden 0 1 2 3 4 5 6 7 8 9 10 a gift

15. Over the past two (2) days, the world has been:

an 0 1 2 3 4 5 6 7 8 9 10 caring and
impersonal responsive to
unfeeling place my needs

16. Over the past two (2) days, I have felt supported:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

12. Over the past two (2) days, I have felt that I have:

no control 0 1 2 3 4 5 6 7 8 9 10 complete control over my life

13. Over the past two (2) days, I felt good about myself as a person.

completely disagree 0 1 2 3 4 5 6 7 8 9 10 completely agree

14. To me, the past two (2) days were:

a burden 0 1 2 3 4 5 6 7 8 9 10 a gift

15. Over the past two (2) days, the world has been:

an impersonal unfeeling place 0 1 2 3 4 5 6 7 8 9 10 caring and responsive to my needs

16. Over the past two (2) days, I have felt supported:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

- I. **INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <i>all</i> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some- what [2]	Quite a Bit [3]	Very Much [4]
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						

Patient's Name _____ Date ___ / ___ / ___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. INSTRUCTIONS: Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <i>all</i> the symptoms you have had during the PAST WEEK.	→ → IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Hair loss						
Constipation						
Swelling of arms or legs						
“I don’t look like myself”						
If you had any other symptoms during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you.						
1.						
2.						

II. Below are other commonly listed symptoms. Please indicate if you have had the symptom **DURING THE PAST WEEK**, and if so, how **OFTEN** it occurred.

Check <i>all</i> the symptoms you have had during the PAST WEEK	→ → IF YES, How OFTEN did it occur?				
	Yes [✓]	Rarely [1]	Occasionally [2]	Frequently [3]	Almost Constantly [4]
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

Thank you so much for taking the time to tell me about your experiences in moving from the hospital to the NH. Your insight is tremendously helpful to me.

A3: Caregiver Interview Guide

Study # _____

Date (T0) _____

Care Transitions: A Mixed Methods Study Using a Complexity Science Lens

Caregiver Interview Guide

Carol Geary, RN MBA PhD-c
Principal Investigator
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University of Nebraska
College of Nursing
Omaha, Nebraska 68198-5330

IRB #358-13-EP Care Transitions: A Mixed Methods Study Using a Complexity Science
Lens
Funded by NINR of the National Institutes of Health under award number
1F31NR013596-01A1.

Interview Dates:

Inpatient: _____

NH Wk 1: _____

NH WK 2: _____

NH WK 3: _____

NH WK 4: _____

Final: _____

Readmission / Near miss dates:

Inpatient Interview CAREGIVER

Introduction

Script for the interviewer:

First, let me thank you for agreeing to participate in this study. I know that you have many concerns right now. If at any point you would like to take a break or have me come back at a later time, please let me know and I will be happy to do so.

The experiences that you share with me will help nurses and other health care professionals better understand what it is like to move from a hospital to **skilled nursing or rehab** care in a nursing home.

Let me begin by giving you an idea of where we are going in these interviews. First, I want to explain that I define transition broadly. It is more than the move from the hospital to the NH for **PT NAME**. It includes anything that you believe is important to **PT's** health and well-being.

I would like to hear about your perspective of transitioning from the hospital to the nursing home. I would like to begin with your experiences here in the hospital, learn about the decision to move into a NH for **skilled nursing or rehab** and your expectations for the NH.

Before we begin, do you have any questions about the interview?

Part One: Hospital experiences

Interview:

Let's begin with your description of your relationship to **PT**. How did you come to be a caregiver for **PT** and what does it mean to you to be **his/her** caregiver?

Let's go back to the beginning of **PT's** hospitalization. What brought **him/her** to the hospital and how did you come to the decision to go to **the NH**?

The goal here is a story. No specifics / dates. Only interrupt for clarification, not details. If the patient gets off subject, use directive interviewing techniques to get back to the subject. If the patient does not communicate in narrative form, then use more specific probes:

What brought **PT** to the hospital?

What has your / their experience been here?

Who do you rely on for help while you are here? (family, friends, etc.)

How did you come to the decision to have **PT** go to a NH? (*aiming for process and contributors*)

How did you choose **the NH**?

Next, get the caregiver's response to the decision:

What you think and feel about **PT** going to **the NH**?

Specific probes:

What are your concerns or fears about going to **the NH**?

What are your goals while **PT** is at **the NH**?

What are the things that give **PT** joy? How will those things be in **the NH**?

Is there anything else that I should have asked you about your experiences in caring for **PT** in the hospital and planning for transition to the NH?

p

Thank you, again, for taking the time to talk with me.

From here, I will check in to see **PT** each day until **he / she** goes to **the NH**. A day or two after **he/she** arrives there, I will ask to sit down with you again for a discussion like this one.

Do you have any questions?

SNF Admission Interview CAREGIVER

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences in transitioning *PT* from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and that this is difficult while you are dealing with *PT's* illness. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This information will help us to improve care in the future.

My questions this time are very similar to those that I asked in the hospital. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since we last spoke in the hospital. Before we begin, do you have any questions about the interview?

Ok, now let's begin. Last time we talked about..... (summarize briefly). Starting then and coming up to today, what has happened?

How have your thoughts and expectations of *the NH* changed since arriving?

Specific probes:

When we spoke last, you described being concerned or fearful of.... (summarize). How has this been since you arrived?

You spoke of your goals(summarize) how have they changed or stayed the same?

You described the things that give **PT** joy....(summarize). Have you found those things here?

Is there anything else that I should have asked about the transition from hospital to NH?

Thank you, again, for taking the time to talk with me.

From here, I will check in to see how you are a couple of times each week. There will not be anything formal again for about 4 weeks or until you leave ***SNF or rehab care.***

Do you have any questions?

Day 30 Interview CAREGIVER

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences as *PT* transitioned from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and I appreciate your taking the time to talk with me. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This will help us to improve care in the future.

My questions this time are very similar to those that I asked in the hospital and when you first arrived here. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since you first arrived here.

Before we begin, do you have any questions for me?

Ok, now let's begin. Last time we talked about..... (summarize briefly). Starting then and coming up to today, what has happened?

How have your thoughts and expectations of *the NH* changed since arriving?

Specific probes:

When we spoke last, you described being concerned or fearful of.... (summarize). How has this been since you arrived?

You spoke of your goals(summarize) how have they changed or stayed the same?

You described the things that give **PT** joy....(summarize). Have you found those things here?

Is there anything else that I should have asked you about your experiences in the NH?

Thank you, again, for taking the time to talk with me.

From here, I will check in to see how you are a couple of times each week. There will not be anything formal again for about 4 weeks.

Do you have any questions?

Day 60 Interview CAREGIVER

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences in transitioning *PT* from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and I appreciate your taking the time to talk with me. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This will help us to improve care in the future.

My questions this time are very similar to those that I asked when we spoke previously. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since we last spoke.

Before we begin, do you have any questions for me?

Ok, now let's begin. Last time we talked about..... (summarize briefly). Starting then and coming up to today, what has happened?

How have your thoughts and expectations of *the NH* changed since arriving?

Specific probes:

When we spoke last, you described being concerned or fearful of.... (summarize). How has this been since you arrived?

You spoke of your goals(summarize) how have they changed or stayed the same?

You described the things that give *PT* joy....(summarize). Have you found those things here?

Is there anything else that I should have asked about your experiences over the last month?

Thank you, again, for taking the time to talk with me.

From here, I will check in to see how you are a couple of times each week. There will not be anything formal again for about 4 weeks or until you leave ***SNF or rehab***.

Do you have any questions?

Day 90 Interview CAREGIVER

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences in transitioning *PT* from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and I appreciate your taking the time to talk with me. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This will help us to improve care in the future.

My questions this time are very similar to those that I asked when we spoke previously. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since we last spoke

Before we begin, do you have any questions for me?

Ok, now let's begin. Last time we talked about..... (summarize briefly). Starting then and coming up to today, what has happened?

How have your thoughts and expectations of *the NH* changed since arriving?

Specific probes:

When we spoke last, you described being concerned or fearful of.... (summarize). How has this been since you arrived?

You spoke of your goals(summarize) how have they changed or stayed the same?

You described the things that give **PT** joy....(summarize). Have you found those things here?

Is there anything else that I should have asked you?

Thank you, again, for taking the time to talk with me.

From here, I will check in to see how you are a couple of times each week. There will not be anything formal again for about 4 weeks or until you leave **SNF or rehab**.

Do you have any questions?

Final (Day 120) Interview CAREGIVER

Introduction

Thank you for continuing in my study. I appreciate your taking the time to talk with me about your experiences in transitioning from the hospital to *the NH for SNF or rehab*. I know this study requires your time and attention and I appreciate your taking the time to talk with me. If at any point while we are talking you would like to take a break or if you would like to skip a question, just let me know and we will do so.

As you may recall, this study will help us understand what it is like to transition from hospital to a NH for skilled nursing care or rehab. This will help us to improve care in the future.

My questions this time are very similar to those that I asked when we spoke previously. Your answers, though, may be very much the same or may be quite different. It is your experience, whatever it may be, that I am interested in hearing about.

Just as we did last time, I will begin by asking questions about what has been going on since we last spoke.

Before we begin, do you have any questions for me?

Ok, now let's begin. Last time we talked about..... (summarize briefly). Since then, much has changed. *PT* is now *acknowledge residence*. Tell me about your experiences since our last conversation.

The goal here is a story. Probes should be for clarification rather than details. If the patient gets off subject, use directive interviewing techniques to get back to the subject. If the patient does not communicate in narrative form, then use more specific probes:

How did you come to the decision to come here?

How was planning to come here? (decision, support people, glitches, etc)

How have things been since you arrived here? (support, successes, problems, etc)

How have your thoughts of **the NH** changed since **the move**?

Specific probes:

In the hospital, you described being concerned or fearful of.... (summarize). After **nearly 3 mos**, how has your perception of this changed?

You spoke of your goals(summarize how they changed over time) what is your perception of those goals now?

You described the things that give you joy....(summarize). Have you found those things **here**

Is there anything that I have not asked you about your experiences that you consider important for me to understand?

Thank you so much for taking the time to tell me about your experiences in moving PT from the hospital to the NH. Your insight is tremendously helpful to me.

This is our last scheduled conversation. I will not contact you again for interviews. You are welcome, though, to contact me using the information on your consent form.

As we discussed during our first meeting, I will use the things that we have discussed to help nurses and other health care providers to improve care for patients

who are transitioning from the hospital to a nursing home for skilled care. I plan to publish the results from this study and will include your story, but will protect your identity.

Thank you, again.

Appendix B: Quantitative Tools

B1: Memorial Symptom Assessment Scale – Short Form

B2: McGill Quality of Life Questionnaire

B3: Socio-demographic and Medical Data

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. **INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						

Patient's Name _____ Date ___ / ___ / ___ ID # ___

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

I. INSTRUCTIONS: Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <i>all</i> the symptoms you have had during the PAST WEEK.	→ → IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Hair loss						
Constipation						
Swelling of arms or legs						
"I don't look like myself"						
If you had any other symptoms during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you.						
1.						
2.						

II. Below are other commonly listed symptoms. Please indicate if you have had the symptom **DURING THE PAST WEEK**, and if so, how **OFTEN** it occurred.

Check <i>all</i> the symptoms you have had during the PAST WEEK	→ → IF YES, How OFTEN did it occur?				
	Yes [✓]	Rarely [1]	Occasionally [2]	Frequently [3]	Almost Constantly [4]
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

MCGILL QUALITY OF LIFE QUESTIONNAIRE

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

- **If you are not even a little bit hungry, you would circle 0.**
- **If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.**
- **If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.**
- **If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.**
- **If you are extremely hungry, you would circle 10.**

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 excellent

PART B: Physical Symptoms or Physical Problems

(1) For the questions in Part "B", please list the PHYSICAL SYMPTOMS OR PROBLEMS which have been the biggest problem for you over the past two (2) days. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shortness of breath, lack of appetite, sweating, immobility. Feel free to refer to others if necessary)

(2) Circle the number which best shows how big a problem each one has been for you
OVER THE PAST TWO (2) DAYS.

(3) If, over the past two (2) days, you had NO physical symptoms or problems, or only one or two, answer for each of the ones you have had and write "none" for the extra questions in Part B, then continue with Part C.

1. Over the past two (2) days, one troublesome symptom has been: _____
 (write symptom)
 no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

2. Over the past two (2) days, another troublesome symptom has been: _____
 (write symptom)
 no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

3. Over the past two (2) days, a third troublesome symptom has been: _____
 (write symptom)
 no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

4. Over the past two (2) days I have felt:
 physically terrible 0 1 2 3 4 5 6 7 8 9 10 physically well

PART C												
Please choose the number which best describes your feelings and thoughts OVER THE PAST TWO (2) DAYS.												
5. Over the past two (2) days, I have been depressed:												
not at all	0	1	2	3	4	5	6	7	8	9	10	extremely
6. Over the past two (2) days, I have been nervous or worried:												
not at all	0	1	2	3	4	5	6	7	8	9	10	extremely
7. Over the past two (2) days, how much of the time did you feel sad?												
never	0	1	2	3	4	5	6	7	8	9	10	always
8. Over the past two (2) days, when I thought of the future, I was:												
not afraid	0	1	2	3	4	5	6	7	8	9	10	terrified
9. Over the past two (2) days, my life has been:												
utterly meaningless and without purpose	0	1	2	3	4	5	6	7	8	9	10	very purposeful and meaningful
10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:												
made no progress whatsoever	0	1	2	3	4	5	6	7	8	9	10	progressed to complete fulfillment
11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:												
completely worthless	0	1	2	3	4	5	6	7	8	9	10	very worthwhile

12. Over the past two (2) days, I have felt that I have:												
no control over my life	0	1	2	3	4	5	6	7	8	9	10	complete control over my life
13. Over the past two (2) days, I felt good about myself as a person.												
completely disagree	0	1	2	3	4	5	6	7	8	9	10	completely agree
14. To me, the past two (2) days were:												
a burden	0	1	2	3	4	5	6	7	8	9	10	a gift
15. Over the past two (2) days, the world has been:												
an impersonal unfeeling place	0	1	2	3	4	5	6	7	8	9	10	caring and responsive to my needs
16. Over the past two (2) days, I have felt supported:												
not at all	0	1	2	3	4	5	6	7	8	9	10	completely

**Socio-Demographic Information
Hospitalized Older Adults' Care Transitions**

Study ID number

Patient Information:

Age Gender Marital Status

Education Race Income

Place of residence

Length of time at residence Urban / Rural?

Method of Payment

Caregiver information:

Relationship to patient

Age Gender Marital Status

Race / ethnicity Location of home

Education

HCP Socio-demographics
Hospitalized Older Adults' Care Transition

Age	<input type="text"/>	Gender	<input type="text"/>	Race /ethnicity	<input type="text"/>
Education	<input type="text"/>				
Prof. certifications	<input type="text"/>				
Experience (yrs)	<input type="text"/>				
Current role	<input type="text"/>				
Years in current role	<input type="text"/>				

Appendix C: Documents related to IRB approval

C1: IRB approval letter



NEBRASKA'S HEALTH SCIENCE CENTER

Office of Regulatory Affairs (ORA)
Institutional Review Board (IRB)

August 26, 2013

Carol R. Geary, RN, MBA
College of Nursing
UNMC - 5330**IRB #: 358-13-EP****TITLE OF PROTOCOL: Care Transitions: A Mixed Methods Study Using a Complexity Science Lens****DATE OF EXPEDITED REVIEW: 07-15-2013****DATE OF FINAL APPROVAL AND RELEASE: 08-26-2013 VALID UNTIL: 07-15-2014****CLASSIFICATION OF RISK: Minimal****EXPEDITED REVIEW CATEGORY: 45 CFR 46.110; 21 CFR 56.110; Categories 5, 6 & 7**

The IRB has completed its review of the above-titled protocol. The IRB has determined you are in compliance with HHS Regulations (45 CFR 46), applicable FDA Regulations (21 CFR 50, 56) and the Organization's HRPP policies. Furthermore, the IRB is satisfied you have provided adequate safeguards for protecting the rights and welfare of the subjects to be involved in this study. This letter constitutes official notification of final approval and release of your project by the IRB. You are authorized to implement this study as of the above date of final approval.

Please be advised that only the IRB approved and stamped consent forms can be used to make copies to enroll subjects. Also, at the time of consent all subjects must be given a copy of *The Rights of Research Subjects* and "What Do I Need to Know" forms.

The IRB wishes to remind you that the PI is ultimately responsible for ensuring that this research is conducted in full compliance with the protocol, applicable Federal Regulations, and Organizational policies.

Finally, under the provisions of this institution's Federal Wide Assurance (FWA00002939), the PI is directly responsible for submitting to the IRB any proposed change in the research or the consent forms. In addition, any adverse events, unanticipated problems involving risk to the subject or others, noncompliance, and complaints must be promptly reported to the IRB in accordance with HRPP policies.

This project is subject to periodic review and surveillance by the IRB and, as part of the Board's surveillance, the IRB may request periodic progress reports. For projects which continue beyond one year, it is the responsibility of the PI to initiate a request to the IRB for continuing review and update of the research project.

On behalf of the IRB,

A handwritten signature in black ink that reads "Kevin J. Epperson".

Kevin J. Epperson, CIP
IRB Administrator
Office of Regulatory Affairs

Appendix D: Principal Case Summaries

D1: Principal Case Summaries

Appendix D: Principal Case Summaries

Each of the principals came into the hospitalization with multiple advancing chronic illnesses. However, each also came with their own unique perspectives on their overall health and wellbeing. Circumstances of the hospitalization, whether perceived as acute events or the culmination of a series of events, did not alter the principal's consideration of his or her health. Rather, the principals most commonly considered that they needed something that was missing to help them get back to what they termed 'normal.' Each principal's experience is briefly described here.

Eva, who had chronic obstructive pulmonary disease and hypertension, described her health prior to the hospitalization: "I was healthy. I mean I, oh yeah, I only took a high blood pressure medicine and a 325 mg aspirin a day. That's all the medicine I was on...I never had oxygen at home." She minimized the importance of the inhalants and nebulizers that she used to control her chronic obstructive pulmonary disease in her description. Although she experienced two readmissions prior to her discharge home, she minimized the importance of the entire episode to her long term health. As an example, although she had not been without oxygen during the case, she declined it at home: "That means I'll have to drag something around? ... I don't really want to wear it all the time. I want to live too." In fact, she rejected all but one of the medications added during her hospitalization. She did leave with a walker, but considered that it would not be needed long term. She made sense of the events by considering them an anomaly.

John struggled to make sense of his circumstances following a clinic visit for viral symptoms that resulted in hospital admission and imminent SNF placement. "You don't know. You're at home, when you have nothing. You go to the doctor's office... Then, you get thrown

into the hospital... and you still don't know that you're going to be there for x number of weeks. You don't know you're going to be at any of these places...You're not planned for any of this." He viewed himself as "normal" prior to this admission, recently retired, but quite independent. However, he saw himself differently at the time of our initial conversation "I'm moving like I'm old people. I'm just not moving." For him, it was not his health that was the concern, he was confident that he "could cope" at home, rather it was the imposed patient status. He resented his impending SNF placement, but ultimately complied with HCP insistence that he go. He spoke of the anticipated transition angrily at times. At others, he was resigned to the SNF admission, "I think it's you have to go because you **have** to go, **you have no other options.**"

For **Mary**, a fall caused a change in her mobility. Over the course of two weeks following, she developed infections that lead to her admission. However, her functional abilities had been declining for some time. Her family had been supporting her in this decline. Mary's memory of her admission to the hospital was limited: "Well, I fell like a couple of weeks ago or something and then, my daughter came over and I was like short of breath so they brought me in here." When asked what they found when she arrived at the emergency room she responded: "I can't even remember...My daughter will be here. My daughter will know," Over the course of the hospitalization, she began to consider that there would be a new 'normal,' alluding to her age and her need for help. After admission to long term care was complete, she shared, "I, probably you know, would like to be at home, in my own home, but, then you know, I can't be." Mary's family acknowledged that she would likely not return home during the initial hospitalization. Mary retained hope for a return home until after she was told she would be admitted to long term care.

Lou went back seven months to describe a series of injuries and illnesses that “started my health on a downward transition.” In addition to diabetes, chronic obstructive pulmonary disease, and congestive heart failure, this principal experienced injuries and an antibiotic resistant infection. An acute inflammation resulted in an earlier admission. The index hospitalization within this study was for acute renal failure. Over the course of a SNF admission hampered by a series of setbacks related to sequela of earlier treatments, this principal echoed his first goal: “I just want to get my strength back so I can go home.” In fact, when he was discharged from the SNF to home, he was immensely concerned that his family could not manage with the sequela. His strength, which had improved initially, was waning. “I’m just sluggish, I guess you’d say or just, just down from where I was like a week ago...And, then, I worry about not wanting to go home, feeling this way.” In our final visit in his home, Lou began to consider that he might be nearing death. Up until that point, he always considered that there would be another option. “I am just generally weaker and all of this stuff (worsening vision, potential need for an invasive procedure, continued sequela) that has all been piling in and worrying about the insulin now and worrying about this, and it is just worrisome.”