HOSPITAL DISCHARGE DESTINATION DECISIONS: EXPLORING CONGRUENCE IN FRAIL ELDERS, THEIR FAMILY MEMBERS, AND HEALTH CARE TEAMS' DECISIONS

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by

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DEDICATION PAGE

To my husband Sid who has been unwaveringly supportive
To my daughter Katie who is my inspiration for the future
In memory of my son Adam who has been my angel the last 4 years
In memory of Joe who was supportive in the face of death

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ABSTRACT

This study used a mixed method design to explore congruence about the discharge destination decision of hospitalized frail older adults, their family members, and health care team members (HCTMs). There were 3 aims to this study. First, using the Control Preferences Scale (CPS), preferred level of participation (LOP) in the hospital discharge decision for frail older adults was established. Second, the extent that congruence between preferred LOP and actual LOP occurred for each participant was ascertained. Lastly, using the participants' perceptions of the discharge destination decision will be described. This finding revealed there was no common pattern of preferred LOP either among individuals, or in the triad. Congruence in the discharge destination occurred in the triad regardless of whether or not individual participants obtained their preferred LOP. There was more congruence with discharge destination decisions (a) in those triads that demonstrated ongoing communication with one another, (b) in which there was not a perceived safety issue for the older adult, (c) when post hospital care was not medically complex for families to manage, and (d) when the older adults were returning to an environment of their choice. The use of rehabilitation post-hospital stay was routine among the sample for frail elders, and HCTMs often avoided discussing permanent nursing home admission by suggesting temporary placement in skilled nursing facilities for rehabilitation. By so doing, the decision of moving permanently to the nursing home was not openly addressed by patients, families, or HCTMs. “Safety” for the HCTMs meant physical safety, medication safety, and confidence in the older adult or caregivers’ ability to manage at home. If any of these basic issues were compromised it was likely that a hotline call by HCTMs to the State Division of Senior Services for potential self neglect would be made. Limitations of the study included a small sample from a single hospital, and that one family member and one HCTM were interviewed for each older adult participant. Additionally, the hospital environment was noisy and chaotic, making it difficult for older adults to communicate during the interviews. Clinical implications include improving communication with the patient about their care and condition by using methods that will make the HCTM more accessible to the patient such as: (a) walking bedside report, and (b) making routine multidisciplinary rounds at the patients’ bedside, and (c) development of a capacity assessment.

CHAPTER 1

Background and Significance

Decisions about discharge from the hospital impact approximately 11.7 million frail older adults and their families annually (Desai, Zhang, & Hagan-Hennessy, 1999). There is little known about what factors influence the discharge destination decisions made by older adults after hospitalization for an acute illness. There is even less known about how older adults, their family members, and health care team members (HCTM) work together to make decisions about the older adult's discharge destination. The decision about where to go after leaving the hospital is particularly cogent for frail older adults who may have difficulty caring for themselves after an illness and may also lack the family support to help care for them at home after hospital discharge. Furthermore, illnesses that have a minimal, short-term effect on younger adults may profoundly impact frail older adults and threaten their ability to live independently in the community setting (Morrow-Howell & Proctor, 1994).

Older adults who are hospitalized are at significant risk for functional decline and the subsequent decrease in their ability to care for themselves at home (Creditor, 1993). Consequently, frail older adults must make discharge destination decisions in the context of continued illness and need for convalescence, while simultaneously facing worsening frailty, which may lead to a greater risk for developing physical impairment, functional limitations, or frank disability. Frail older adults may find that they cannot go home to live unless certain conditions are met, such as daily care provided by family members with or without assistance from formal community resources (Hong, Morrow-Howell, & Proctor, 2004). Other older adults may be too physically ill or debilitated to return home until they have received continued rehabilitation in a nursing home. Still others may find that they have to make the decision to move permanently to a continuing care community, assisted living facility, or nursing home.

Families reported that having an older family member discharged from the hospital is a confusing process, filled with incongruities about the discharge plan and stresses related to inconsistent care providers and lack of discussion about discharge options (Congdon, 1994). Decisions about living arrangements after hospital discharge are often driven by health care experts (Opie, 1998; Nolan, & Dellasega, 2000) with limited input from the patient or family members (Bowles, Foust, & Naylor, 2003; Congdon). This is of particular concern because health care experts know little about older adults' family relationships and daily life. Older adults often prefer to make decisions about their health care in concert with their families (Clark, Hall, & Rosencrance, 2004; Knapp, 1991).

As challenging as it may be to plan for hospital discharge, the reality of actually going home may be more intense and frightening than anticipated by older adults or their family members. Therefore, it is imperative that families remain closely involved with the older adult's care after hospital discharge. Older adults who live alone and do not have adequate social and physical support for care after being discharged from the hospital are at risk for problems related to their illness, rehospitalization, or institutional placement (Forster, Murff, Peterson, Gandhi, & Bates, 2003; Mahoney, Eisner, Havighurst, Gray, & Palta, 2000; Tennstedt, 1999).

The concerns about where older adults will go after discharge and how they will receive necessary help is a vitally important issue that will only become more significant in the future as the number of older adults increase. Frail older adults and their family members will have to face decisions about ongoing care for the older adult that may change the fabric of their daily lives. There is a bias in health care toward achieving decision-making congruence, or agreement, among all those involved in health care decisions.

In his paper about congruence theory, Eckstein (1997) explicated congruence as being in agreement about essential elements. Congruence of frail older adults, family members, and HCTMs about discharge destination decisions of hospitalized older adults has not been addressed in the literature. When congruence has been addressed, the studies have focused on agreement between physicians and patients about medical treatments, or on the importance of achieving preferred roles in decision-making (Bruera et al., 2001; Davison, Degner, & Morgan, 1995; Fried, Bradley, & O'Leary, 2003; Ford, Schofield, Hope, 2003; Jahng, Martin, Golin, and DiMatteo, 2004; Mattimore, et al., 1997; Murray, Pollack, White, and Lo, 2007).

The literature is largely silent on why congruence is perceived as good and incongruence as negative. However, incongruent decisions may involve conflict, also referred to as disharmony by Jacob (1998). Jacob also identified that health care professionals strive to avoid conflict with patients and family members, because it is troubling to them, and viewed negatively by them. This idea of conflict as negative was also seen in Siminoff, Rose, Zhang, and Zyzanski's (2005) study to develop an instrument to measure discord between family members in cancer treatment decision-making, so that clinicians could identify ways to improve communication between families and clinicians to reduce discord. The idea that incongruence may bring with it the potential for meaningful discussions between older adults, family members, and HCTMs was not addressed

The logic of congruence, as identified in the literature in the context of decision-making, is that the greater the congruence the better the decisional outcomes, and the less stressful the decision-making process. However, the extent to which this happens is unclear when older adults, their family members, and HCTMs engage in discharge decision-making. The present will study will explore this logic of congruence, through participants' perceptions of the discharge destination decision-making process.

Background

The 2000 U.S. census reported that adults age 65 and older are growing at a slower rate (12%) than the total population (13.2%). Until 2009 the population growth of the elderly is expected to remain constant with total population growth at approximately 13%. However, starting in 2010 the population of adults over age 65 is expected to begin to dramatically increase as a result of the aging baby boom population, those born from 1946-1964 (Hetzel & Smith, 2001). Beginning in 2010 through 2030, the U.S. population age 65 years and older will grow by approximately 20% per year (Administration on Aging, 2003). The 2000 U.S. census reported 18.4 million people age 65-74 years old (53%), 12.4 million people age 75-84 years old (35%), and 4.2 million people age 85 and over (12%). These age groups respectively represented 6.5%, 4.4%, and 1.5% of the total population (Hetzel & Smith, 2001).

The oldest old as a demographic group are increasing far more rapidly than younger old. During the 1990's the oldest old (those 85 and older) increased by 38%; in contrast those age 75-84 increased by 23% and those 65-74 increased by less than 2% (Hetzel, &

Smith, 2001). Over the next 25 years there will be a marked increase in the elderly dependency ratio (the number of persons 65 years and older for every 100 persons age 18 to 64). Currently the dependency ratio is below 21. Even now it is often difficult for families to garner the necessary resources to care for older adult family members. It is difficult to imagine the challenges that will exist for older adults and their families over the next 25 years when in the year 2030 the dependency ratio is expected to peak at 36 (Administration on Aging, 2003).

The overall demographic picture of older adults is appreciably different than that of the younger U.S. population. Older women continue to outnumber men, resulting in a lower sex ratio of 70 (number of men per 100 women) for those age 65 and older, compared with a sex ratio of 96 for the total population. The sex ratio continues to drop with age, resulting in a sex ratio of 41 for those age 85 and older, which translates to roughly 2 females for every male (Gist & Hetzel, 2004). A greater percentage of older men (75%) than older women (43%) are married. There is a greater number of older women who are widowed (45%) than older men (14%); more older women are living alone than older men (Gist & Hetzel, 2004). Women live longer than men, are less physically strong, and are more prone to suffer from disability and/or frailty.

Disability

Forty-three percent of older women report disability compared with 40.4% of older men. Overall, 59.7% of all people reporting disabilities are women (Waldrop & Stern, 2003). As a demographic group, older adults are more vulnerable to physical impairment and disability than younger adults. People age 65 years of age and older are more likely than those under the age of 65 to report sensory, physical, mental, or self-care disability that cause them to have difficulty leaving their home (Waldrop & Stern). Over half (54.5%) of older adults report having a physical or nonphysical disability of some type, 37.7% report a severe disability (Administration on Aging, 2003). Over 20% of older adults report having difficulty leaving their home to shop or visit the doctor (Waldrop & Stern). Self-care disability is 5 times greater among older adults compared with working age adults' age 16-64 years. Older adults are 6 times more likely to have a sensory disability than working age adults (Waldrop & Stern).

Reported measures of disability often incorporated dimensions of physical functioning. Physical functioning has been assessed using instruments to measure practical dimensions of life such as eating, dressing, and ambulation, commonly known as activities of daily living (ADLs). Instrumental activities of daily living (IADLs) include slightly different dimensions of functioning such as shopping, housekeeping, or bill paying (Kane & Kane, 1981). Over 27% of the non-institutionalized community dwelling elderly reported difficulty performing at least one ADL and an additional 13% reported having difficulty with at least one IADL. Reported difficulty in performing ADLs or IADLs increased significantly with age. Nearly twenty percent of those between age 65 and 74 reported having difficulty with ADLs or IADLs. Of those age 85 and older, 52.5% reported difficulty with ADLs or IADLs (Administration on Aging, 2003).

Frailty

Older adults with functional impairment or disability may also be frail. Fried, Ferrucci, Darer, Williamson, and Anderson (2004) found that frailty was common; over 28% of the women in their study were frail. Frailty is conceptualized in two distinct ways. In one way, frailty is seen as a physical condition associated with decreased physiologic reserve and dysregulation of body systems (Fried et al., 2004). Another is a social conceptualization identifying frailty as a socially constructed problem that includes a dynamic adaptation by older adults and their family (Kaufman, 1994) to accommodate the diminished capacity of the older adult to carry out important practical and social activities of daily living (Raphael et al., 1995).

Frailty has often been associated with advancing age. A community dwelling sample of older adults revealed that few (4.8%) 65-year-olds were considered frail, but among those age 90 and older the percentage increased to 56.3% (Brody, Johnson, & Reid, 1997). Most of those reported as frail had difficulty in mobility tasks (72%), a large percentage had difficulty with IADLs (60%), but far fewer had difficulty with ADLs (27%). Those identified as frail were more likely to be female, African American, have less education, and lower incomes (Fried et al., 2001).

Care and Services

Adults are living longer, but that longer life has, heretofore unknown consequences. Living to very old age may bring with it some serious social problems. When older adults have robust health, enough money, and an involved family, they live relatively comfortably in their old age. When ill, frail, disabled older adults live alone, or with a spouse who has at least as many challenges, in impoverished neighborhoods without adequate social support, the landscape of old age changes dramatically. Finding ways to go to the grocery store, pharmacy, and to the doctor when driving is no longer possible become insurmountable problems for older adults. When illness, frailty, and disability combine to make cooking meals, bathing, getting to the toilet, and cleaning house impossible, outside resources that may or may not be welcomed by the older adult may be called upon to establish what is considered to be reasonable living conditions for the older adult. It is often at the time of hospitalization that problems with older adults' abilities to successfully care for themselves at home are first discovered.

Hospitalization

Hospitalization placed frail older adults at increased risk for requiring home care services or for admission to a nursing home. In 1999, adults age 65 years or older comprised approximately 13% of the population, but accounted for 11.7 million (38%) hospitalizations in the United States (Desai et al., 1999). One factor that placed older adults at significant risk for worsening functional ability was hospitalization (Creditor, 1993; Sager et al., 1996). There were 3,549 hospital discharges for every 10,000 persons in those ages 65 and older. This same age group was hospitalized 3 times more often than younger adults.

The average hospital stay in 2002 for adults over age 65 was 5.8 days, 5 days shorter than hospital stays in 1980 (Administration on Aging, 2003). Even for the oldest old, the average hospital stay was 6 days, which was a decrease from 11 days in 1980 (National Center for Health Statistics, 2004). Although hospital stays were shorter, the medical conditions for which older adults were admitted to the hospital were serious and included malignancies, diabetes, mental illness, congestive heart failure, acute myocardial infarction, ischemic heart disease, cerebrovascular disease, osteoarthritis, pneumonia, and accidental injuries (National Center for Health Statistics, 2004). When older adults leave the hospital they are far from well and generally have an extensive periods of convalescence ahead of them.

Alexy, Elnitsky, and Nichols (1996), in a study of rural elderly, found that in a 1-year period, unplanned hospital readmission rates were 31% for older adults who had previously been hospitalized. Patients were most likely to be readmitted with diagnoses of circulatory disorders (28.3%), respiratory disorders (12.7%), and digestive system disorders (11.2%). The investigators attributed readmissions to shortened primary hospital stays, inadequate community support after discharge and inadequate follow-up with the primary physician.

Nursing home care. In order to safeguard against adverse outcomes such as worsening medical conditions that result in hospital readmissions, health care professionals often encourage frail older adults and their families to consider moving from their community homes to places where they can receive care deemed necessary by the medical community (Brody, Johnson, Ried, Carder, & Perrin, 2002). Approximately 1.6 million older adults are currently living in an institutional setting (Jones, 1999). Of the total population of elderly, 4.5% live in nursing homes and another 5% live in senior housing of all types including those with and without supportive services for ADLs and IADLs (Jones).

Nevertheless, being older increases the probability of living in a nursing home; approximately 18% of elders age 85 and older live in nursing homes compared with 1% of adults age 65-74 (Administration on Aging, 2003). Approximately 1.3 million of the 1.6 million older adults living in nursing homes are female (Goldstein & Damon, 1993). The elderly who live in a nursing home were less likely to be married; only 1 in 7 were married while 3 in 5 were widowed (Goldstein & Damon). Forty-six percent of nursing home residents were admitted from hospitals and 30% came from private or semiprivate residences (Jones, 2002). The elderly often see the move to the nursing home as the least desirable of their options for living arrangements (Johnson, Radina, & Popejoy). The fact that those living in nursing homes are often severely disabled, 94% required bathing assistance, 87% required dressing assistance, 56% required help with toileting, and 47% required help with eating (Jones), illustrates that older adults only move to the nursing home after other options for support at home have failed.

Home health care. Home health care services served as a stopgap measure between staying in the hospital and going to a lower acuity setting, such as a rehabilitation facility or nursing home. Many older adults left the hospital to go home with the help of home health care services. Older adults were often admitted for home health care services for common medical problems such as diseases of the circulatory system (30.8%), including heart disease (13.8%), essential hypertension (5.7%), and cerebrovascular disease (9%), diabetes mellitus (9%), and musculoskeletal and connective tissues diseases [10.2%] (Munson, 1999).

An estimated 1.75 million older adults have used home health services. Most of those who used home health care were women (70%), 47% were age 75-84, 69% were white, 47% were widowed, 92% lived in private residences, and 50% were living with family members (Munson, 1999). Fifty-nine percent of women who received home health services were widowed and 44.3% lived alone (Munson). Those who lived alone were often in special need of personal care services, because they may no longer be capable of caring for themselves and have no one living in their home that can assist them with care.

Personal care services offered by home health agencies are available for a short time, (while the beneficiary is admitted to the home health agency), and include assistance with ADLs and IADLs. Of those who received Medicare personal care services, just less than half (44.1%) received this care 181 days or more (Munson, 1999). The majority of elderly home care recipients (56%) received help with ADLs such as bathing (53.2%), dressing (45.8%), transfer to or from bed or chair (29.6%), and using the toilet (22.6%) (Munson). Women (51%) and men (45%) were equally likely to receive help with IADLs such as shopping (84.3%), doing light housework (38.9%), taking medications (23.4%), and preparing meals (23%). Over 84% of those in home health care received nursing services. Far fewer older adults received other available services, such as help with medications (9.8%), homemaker and household services (28.1%), physical therapy (20%), occupational therapy (4.9%), social services (10.6%), and 1.6% received mental health services (Munson).

When older adults are discharged from home health services their chronic medical conditions often remain a problem requiring ongoing support by family members. Long-term personal care services, while not paid for through Medicare, are available through private pay or Medicaid Waiver programs. However, the recent changes in Medicaid in many states have made these services less available to all people, including older adults.

Of the elderly who were discharged from home health care services, 9.7% of women and 7.9% of men had fully recovered from their illness. Another 21.8% of women and 16.2% of men were discharged because their conditions had stabilized enough that they no longer met the criteria for continued home health care services (Munson, 1999). After discharge from home health care, family and or friends resumed full care for 7.6% of women and 6.8% of men (Munson). While receiving home health care services 11.4% of women and 15.6% of men were admitted to the hospital (Munson). Just over 5% of men and 6% of women were admitted to a nursing home while receiving home health care. Fewer than 5% of women and 7% of men died while receiving home health services (Munson).

Hospital discharge. Hospital discharge to home for frail older adults is a complex process challenging older adults, their family, and health care teams to collaborate in order to avoid the negative outcomes of inadequate discharge planning (Bowles, Foust, & Naylor, 2003; Naylor et al., 1994). It is challenging for health care teams to identify the discharge needs of older adults in an accurate and timely manner (Bowles, Naylor, & Foust, 2002). There is evidence to suggest that a well-organized discharge process including formal case managers increased communication and reduced the risk of rehospitalization (Brown, 1995; Mamon at al., 1992; Naylor et al.). However, there is little known about what information frail older adults and their families want HCTMs to provide about self-care and community services (Naylor & Chapman-Shaid, 1991). There is no information about how older adults, family members, and HCTMs work together to make decisions about hospital discharge.

Discharge destination. Discharge destination decisions for frail older adults are complex, highly personalized, and include influences such as the presence of impairment, functional limitation or disability, problematic living situations, extent of family and community support available, and personal choices about lifestyle. The physical state of frailty puts older adults at risk for developing physical impairment, functional limitations, and disability (Fried et al., 2004). These physical states eventually lead to problems for older adults living alone and taking care of themselves. Frailty becomes a problem that older adults and their families must consider as they make discharge destination decisions after hospitalization.

Significance of the Study

Decisions about where one will go after being discharged from the hospital often seem to be a matter of default. In the minds of younger adults and middle to young-old adults, there seems to be little question they will go home from the hospital. Nonetheless, when the individual being discharged from the hospital is old and frail, the feasibility of returning home from the hospital becomes uncertain. Home, to the recently hospitalized frail older adult, takes on new meaning. Home may be both a safe haven and a place where continued care, treatment, and convalescence must go on. If for some reason, the care that is essential to convalescence cannot be continued at home with or without home health care services after discharge from the hospital, then admission to a nursing home becomes more likely.

Family and other sources of support are often vital elements that allow frail older adults to go home from the hospital. If family members are not able or willing to participate in caring for and supporting convalescence of the older adult, and the older adult does not have access to adequate outside services, then discharge to home becomes less likely.

With the burgeoning elderly population expected to begin in 2010, issues of care after hospital discharge have become critical. Those elderly persons age 85 and older, who are prone to problems associated with frailty, are expected to increase in number more rapidly over the coming decades than are the younger elderly. Spouses are often the family members of choice to support care after hospital discharge; however very old women and men may not have living spouses. If older men and women do not have children or stepchildren who are willing and able to assist them, they may find themselves without the necessary community support sources to remain at home. Additionally, women in the oldest old age group live alone and in poverty disproportionately more often than the rest of the population, making it very difficult to purchase the services needed to remain at home safely and successfully after discharge from the hospital (Katz, Kabetos, & Langa, 2000).

Many healthcare institutions that work with the frail elderly are simply not prepared for the dramatic demographic changes that will begin in 2010. For healthcare professionals, problems that will accompany this demographic must be planned for now. It is vitally important that healthcare professionals, who work with older adults and their families, understand more about how families work together to make important decisions about the discharge destination. Challenges such as poverty, disability, frailty, mental confusion, and isolation from the community are just a few of the issues faced by older adults and their families in today's society. How problems of social and physical support for care of the elderly are addressed and negotiated with both the elder and their family has implications for decisions about discharge destination.

Decisions about discharge destinations of older adults are not made in isolation, but are part of a complex tapestry that is woven from the viewpoints and values of the older adults, their family, and HCTMs. Each member of this triad has a level of participation that they prefer to use when making health care decisions. At the present time there is little known about how those with differing needs for participation in decisions, and different viewpoints about the available choices, resolve the issues and problems that commonly occur as discharge destinations are being negotiated between the frail older hospitalized adult, their family members, and HCTMs.

Research Questions

The proposed study will explore congruence about the discharge destination decision of hospitalized frail older adults, family members, and HCTMs. Specific aims include:

1. To describe the preferred level of participation (LOP) in the discharge destination decision of (a) the frail older hospitalized adult, (b) the same older adult's identified family member, and (c) the HCTM most involved in the decision.
2. To identify the extent that congruence between preferred LOP and actual LOP about the discharge destination decision occurred individually and as a triad for the same individuals.
3. To describe the participants' perceptions of the discharge destination decision.

Definition of Terms

For the purpose of this study, the following terms are defined:

- Older adults are those age 70 and older.
- Family is whomever the older adult identifies. Family members may be related biologically, by marriage, or may be fictive kin.

- Healthcare team member is a single member of the health care team who has prepared the older adult for discharge. This individual may be a nurse, outcomes coordinator an RN, or social worker.
- Discharge destination is the place that the older adult plans to go immediately after discharge from the hospital.
- Decisional congruence is broadly defined as agreement about the essential elements of the discharge destination decision between the older adult, their family members, and HCTMs (Eckstein, 1997).
- Frailty is a physical condition associated with decreased physiologic reserve and dysregulation of body systems (Fried et al., 2004). For this study a score of ≥ 2 on the Frailty Phenotype will be indicative of physical frailty (Fried et al., 2001).
- Intact cognition is defined as a score of ≥ 3 on the Short Form Mini Mental Status Exam (SMMSE).
- Functional limitations are restrictions in performing physical and mental activities used in daily life. The demands of the situation do not affect functional limitation (Verbrugge & Jette, 1994).
- Disability is inability to do activities in any domain of life due to a health, physical, or mental problem. Disability is the gap between individual capability and the demands of an activity. It is the demonstration of functional limitations in a social context (Verbrugge & Jette, 1994).
- Activities of daily living (ADL) are activities related to personal care including bathing, showering, dressing, getting in and out of bed or a chair, using the toilet, and eating (Kane & Kane, 1981).

- Instrumental activities of daily living (IADL) are activities related to independent household management including preparing meals, managing money, shopping for groceries or other necessities, performing housework, and using a telephone (Kane & Kane, 1981).
- Community dwelling refers to individuals who live in the general community either in their individual homes, apartment, independent living section of a continuing care requirement community, or setting other than a nursing home or assisted living facility.
- Nursing home refers to an institution that offers 24-hour nursing protective oversight and skilled nursing care to residents who cannot negotiate an independent pathway to safety. Care is paid for privately, or through the Medicare or Medicaid programs.
- Assisted living refers to a facility that offers basic 24-hour protective oversight, but not 24-hour skilled nursing care, to residents who can negotiate an independent pathway to safety. Care is paid for privately or through insurance.
- Home health care services are medically necessary short-term acute care related activities paid for through insurance or through Medicare.
- Personal Care Services are short or long term personal or homemaker services paid for privately, through insurance, Medicare, or Medicaid Waiver programs.
- Hospital admission is defined as an inpatient stay for any reason that lasts more than 23 hours.

- Discharge planning is a process of comprehensive assessment of a patient's needs during hospitalization and projected needs after discharge, including coordination and implementation of the discharge plan (Naylor, 1990).
- Discharge destination includes any location in the community, including private homes, private apartments, nursing homes, assisted living facilities, or supervised apartments.
- Preferred level of participation (LOP), is the amount of decision-making participation an individual wants to assume when making decisions about health care (Degner, Sloan, & Venatesh, 1997, p.24).
- Decision-making role refers to the continuum of decisional preferences identified in the Control Preferences Scale. There are three major roles, active, passive, and collaborative (Degner et al., 1997, p.24).

Conclusion

It is very difficult for the professionals who work with frail older adults and their families to fully appreciate the degree of stress and difficulty associated with discharge destination decisions. The decision to go home from the hospital is often accompanied by a series of choices about what kind of services need to be rallied to support living at home. Decisions about going to a nursing home or to other supportive living environments often occur because the older adult, their family members, and HCTMs have decided that the care that the older adult requires as a result of their illness cannot be adequately addressed in their current living situation. Each time an older adult is admitted to the hospital it becomes increasing likely that alternative options for care or living are explored. There is no research that has explored this complex topic of discharge destination decision-making from the viewpoints of frail older adults, their family members, and HCTMs. This research offers a significant contribution to the understanding of how people work together to make very difficult and life-altering choices about how to receive needed care and services and where to live after hospital discharge.

CHAPTER 2

Literature Review

Hospitalized frail older adults often experience an exacerbation of physical conditions and impairments that compromise their ability to return home (Morrow-Howell & Proctor, 1994). When physical impairment is coupled with weak social support, older adults who live in the community are often not able to return to their homes after an acute illness (Allen & Ciambrone, 2003). Clinicians who work with older adults recognize the deleterious effects of a hospital admission on frail older adults' capability to function and live independently in the community (Creditor, 1993; Naylor et al., 1994). Adults age 65 years of age or older comprised 13% of the population, but accounted for 11.7 million (38%) hospitalizations in the United States (Desai et al., 1999). The combined effect of hospitalization, frailty, and the need for post-hospital care makes the decisions that surround hospital discharge dynamic and complicated. Although this area of study has significant implications for the care of older adults, little work has been done that examines the discharge process (National Institutes of Nursing Research, Hospital Care, 2004) and no work has been done examining the hospital discharge destination decision from the viewpoint of frail older adults, their family members, and the health care team members (HCTM).

Decision-making

Decision theorists Tversky and Kahneman (1981) defined a decision problem as "the actions or options among which one must choose, the possible outcomes or consequences of those acts, and the contingencies or conditional probabilities that relate the outcomes to the acts" (pp. 453). Baron (2000) simply identified decisions as choices or actions about what to or not to do, based on beliefs about what actions need to occur to achieve specific goals. Decision-makers use a search and inference framework for thinking about the choices to consider when making decisions. The decision-maker must consider the options that are available, however, he or she first must have some doubt about the best course of action, which leads to a search to remove the doubt, and an inference about what the most reasonable choice would be (Baron, 2000). Simply put, making a choice is the action of deciding between two options (Jones et al., 1998). Ultimately, decision-making can be viewed as a problem-solving process that is controlled by how the problem is formed or framed, and by the norms, habits, beliefs, and personal characteristics of the individual making a decision (Baron; Tversky & Khaneman). All decision-making theories incorporate to a greater or lesser degree the process used by people of diverse backgrounds, values, and beliefs to form judgments and make decisions.

There are a considerable number of theories that have been developed over centuries to explain how human beings make decisions. As early as the 1700’s situations such as the stag hunt were used to describe how decisions were made when people were faced with making choices from which they may not directly benefit. Centuries later the game of the stag hunt became the basis for a classic game theory called prisoner’s dilemma. Early decision-making theorists postulated that winners of the prisoner’s dilemma were compelled by competition, not cooperation (Ridley, 1996). However, in 1979 sophisticated modern computer technology was applied to the prisoner’s dilemma and the old beliefs about how humans made choices were suddenly called into question.

Strategies of cooperation, not competition, did better when computer technology was applied, thus making long-held beliefs about motivation in decision-making obsolete.

Decision-making as a systematic empirical discipline came into being in the 1960’s. Connolly, Arkes, and Hammond (2000) identified key elements that attributed to the explosion of research about decision-making. The first was increased interest in cognitive psychology, which includes the study of memory, thinking, problem solving, and language. There was also a reduced area of interest in motivation and an increased interest in mental activity. During this same period, Freudian psychology and response behavorialism lost favor. By far the greatest reason for the renewed interest in the field was improved computer technology, which gave decision scientists the ability to build human information processing models.

A basic tenet of decision-making science is probability theory. The basis for the normative theory of probability arises from the understanding that there are numerical measures that identity the strength of belief in a certain proposition (Baron, 2000, p. 94). Explained another way, the mathematical theory of probability is a theory of inference, which specifies that the probability of one belief depends on the probabilities of the other associated beliefs. Baron used a simple example to explain probability: if the probability it will rain is 0.8 then the probability that it will not rain is 0.2. There are two choices that can be made as you walk out the door in the morning. One is take your umbrella it is surely going to rain today. The other is, there is slight chance that it will not rain therefore, and I am not taking my umbrella. The probability theory of decision-making is useful because of the innate desire of people to maximize utility, otherwise known as desired or good outcomes. Probability theory may also appear to be clear-cut because it relies on the mathematical expression of possible outcomes, unlike other decision-making theories which may rely on arguments to define the decision problems.

The most significant normative theory of probability is expected-utility theory (EUT). EUT is the theory of how to measure and maximize utility (Baron, 2000). However, Baron argues that if the main rule for decision-making is to allow us to make the decision that helps us to achieve our ultimate goals then there are problems inherent in EUT. First, theories that use the utility concept do not address whether desirability or goodness should be the only outcome that is considered. Second, decisions often involve making choices between tradeoffs. Tradeoffs are simply different attributes of the same choice and are not significantly different from one another. Third, there are often conflicts among the goals of different people involved which may lead to conflicts in decision outcomes.

EUT is part of a body of work known as Traditional Decision Theory that spans nearly 300 years. Connolly and Beach (2000) argue that most of what has been done to increase the descriptive accuracy of the theories has been largely cosmetic, and that newer less traditional methods of decision-making research are needed. One such theory identified by Connolly and Beach (2000) as a stellar example of a new decision-making theory is image theory. Image theory identifies situation assessment as an essential ingredient for decision-making. Other important elements of the theory are that past experience are fundamental in the decision-making process, intuition and causal reasoning are central components, and feedback received during implementation of a choice is used to guide behavior.

There are yet other theories recognized as new and innovative those incorporate elements not explained in TDT (Connolly and Beach, 2000). Four major theories identified by Connolly and Beach center on situation assessment, past experience, and causal thinking. The first of these theories is Klein's (1989) theory of recognition-primed decision-making. The main element of this theory that decision-maker recognize situations and have a prepared course of action. The second theory is Noble's (1989) cognitive situation assessment, which identifies how a decision-maker views the requirements needed to make a decision and uses past experience as a way to satisfy the needed requirements. Argument-driven decision-making (Lipshitz, 1989) uses causal logic as a means to deal with environmental demands of decision-making situations. The last theory is Pennington and Hastie's (1988) explanation-based decision making, in which situation assessment includes elaboration of the decision-makers' story to include information about what lead up to the present situation and the implications that the story holds for future decisions.

As identified earlier in this section when conflicts arise between decision alternatives, goals, or people, issues of moral reasoning must be addressed. Moral decisions uniformly deal with what should be, not with what is (Baron, 2000, p. 382). When a decision involves the consideration of moral issues, the decision-makers' values and beliefs, cultural beliefs, upbringing, and experiences play a significant role in the choices that are made (Baron). Rachels (2003, p. 14) identified morality as the effort to guide one's conduct by reason; to do what one has the best reason for doing, while simultaneously considering the interests of other affected individuals. When there are questions that arise as to why a decision may not have turned out as intended a part of the answer may lie in the moral reasoning of those making decisions (Baron, 2000).

Many decisions made in the health care arena are complex and involve people with competing interests (Arras, 1995). Not only do family members have competing interests, but members of the health care team themselves have competing interests and disagree about the best course of action. In all people, the process of reasoning, inference, and understanding are shaped by personal assumptions (Hilton & Slugoski, 2000). It is impossible to fully rid ourselves of our values and beliefs to make only information-driven decisions. There are always biases inherent in how information is presented or framed and also how information is interpreted (McNeil, Pauker, Sox, Tversky, 2000).

After hundreds of years, decision theory is now broadening to reflect the complexity of life, where people make decisions in situations where there are possibly no clear answers. Health care decision-making certainly offers challenges in how to achieve congruence between people involved in the decisions. For many frail older adults, family members, and health care team members, one such decision may be the decision about hospital discharge destination decisions.

Decisions about Discharge

Patients have frequently reported not being involved in discharge decisions (Brown, 1995). As identified in the previous chapter, decisions have been found to be expert driven and heavily influenced by the health care providers with minimal input from families and even less input from the patient (Congdon, 1994; Nolan & Dellesaga, 2000; Opie, 1998). However, not all frail older adults or their families desire the same degree of involvement in the decision-making process. Benbassat, Pilpel, and Tidhar (1998) identified roles of involvement in health related decision-making as (a) active, (b) collaborative, (c) passive, and (d) avoiding information. Similarly, Degner, Sloan, and Venkatesh (1997) identified three major preferences for involvement in decision making as (a) active, (b) passive, and (c) collaborative. Several studies have identified that those who preferred a more passive role in health related decision-making were sicker, less educated, from a minority ethnic group, male, and elderly (Benbassat et al.; Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988). Ultimately, the level of preferred decision-making involvement may be due to the complex relationship between the frail older adult, their family members, and HCTMs (Davison, Degner, & Morgan, 1995; Shawler, Rowles, & High, 2001).

Degree of involvement may be impacted by beliefs about role expectations of different family members and the HCTMs, the nature of the decision, the severity of illness, and prior experiences (Mansall, Poses, Kazis, & Duefield, 2000). Kaufman (1994) found that frail people who became hospital patients often viewed the solutions to their life problems offered by the health care team as inadequate and intrusive. The reality is that frail older adults may not desire exclusive decision-making autonomy but would like to share decision-making authority with their family (Hawkins, Ditto, Danks, & Smucker, 2005; Knapp, 1991; Roberto, 1999). In particular, older adults confer upon their family the right to deviate from their written health care directives in medical situations where it makes sense to do so (Hawkins et al.).

The ideal of autonomy as the highest ethical principle to uphold in health care decision-making has lately come under criticism (Drought & Koenig, 2002; Hawkins et al., 2005). To be autonomous means to be an independent, rational decision-maker, who knows one’s own desires and preferences and whose freedom is expressed in actions taken to fulfill those desires or preferences (Agrich, 1995). This definition can be potentially problematic for frail older adults who may not be completely independent either cognitively or physically. Decisions made by older adults are not made in isolation from their families but are made within social networks that include the older adult, their family, and the institutions that are involved in their care (Callahan, 2002). Families have a circle of needs that include cognitive, emotional, relational, and value needs (Callahan). Within the context of family decisions there are trade-offs and compromises among those who had competing interests (Arras, 1995; Hanks, 1993). Callahan reminded us that it is essential to remember that decisions have consequences and individual autonomy is to be respected but not imposed on families.

Nevertheless, when the confusing nature of the team approach to care and discharge planning is coupled with the older adult’s choice to have multiple family involved in discharge decisions, problems occurred with accurate assessment of the frail older adults’ self care capabilities and discharge care needs (Clark, Hall, & Rosencrance, 2004; Congdon, 1994; Oktay et al., 1992; Proctor, Morrow-Howell, & Kaplan, 1996). One study showed that (Reiley, Iezzoni, Phillips, Davis, & Tuchin, 1996) all too often nurses and physicians did not identify functional impairment of frail older adults because they failed to formally assess functional status. If family members were not were not aware of, or accurately informed about, the frail older adult’s degree of functional impairment they may not have been in a position to effectively and safely support care at home.

According to Brown (1995) patients and their family members reported satisfaction with the discharge process yet did not always recall receiving basic instructions about treatment follow-up, diet, and medications. Because of shortened hospital stays, patients were receiving discharge instructions while they were still very ill, many did not recall what was taught to them and there were often no family available for teaching at the time of discharge (Brown, 1995; Morrow-Howell et al., 1991). Problems after discharge resulted because of lack of understanding of the discharge plan and the more serious problem of patients having unmet needs at the time of discharge. Mamon (1992) found that over 97% of patients had at least one unmet need at the time of hospital discharge. This is disconcerting because frail older adults often received assistance and support for physical care from their family members after being hospitalized (LeClerc, Wells, Craig, & Wilson, 2002). Consequently, if the discharge plan was not well developed, patients were at significant risk for poorer health outcomes, including hospital readmission because of complications or relapse that occurred as a result of premature discharge from the hospital or unanticipated admission to the nursing home (Allen & Ciambrone, 2003; Anderson, Helms, Hanson, & DeVilder, 1999; Fethke, Smith, & Johnson, 1986; Mamon et al., 1992).

Making decisions about hospital discharge destination for frail older adults involves working with others to reconcile competing values, beliefs, lifestyle, culture, and past experiences of all those involved in the decision. Decisions are more likely to become problems when there are moral or ethical issues surrounding the decision that make achieving congruence between those involved in the decision difficult or impossible.

Discharge Outcomes

The majority of older patients discharged from the hospital are discharged to their homes, with or without home health care, but many return to the hospital because of problems taking care of themselves (Gooding & Jette, 1985; Holloway & Pokorny, 1994; Marcantonio et al, 1999). For example, in one study alone, 18 of 85 were readmitted within 6 weeks, 34 of 85 were readmitted within 6 months, and 44 of 101 patients had been readmitted to the hospital within one year (Fethke et al., 1986). Proctor, Morrow-Howell, Hong, and Dore (2000) found that 42% of elderly patients discharged after a hospital admission for congestive heart failure were readmitted within 14 weeks of hospital discharge.

Studies have demonstrated that frail older adults over age 65 were more likely to be readmitted to the hospital than were adults under age 65 (Baum & Rubenstein, 1987) and this readmission most likely occurred in the first 2-3 weeks after discharge (Anderson et al., 1999; Naylor et al, 1994). Over one-third of all readmissions were preventable (Naylor et al., 2004). Patients were most often readmitted for new medical problems, a relapse, complication of treatment, adverse medication reaction, and problem with caregiver or extended care facility (Marcantonio et al., 1999). As many as 1 in 5 patients discharged from the hospital experienced an adverse outcome related to hospitalization resulting in readmission, emergency room (ER) care, extra lab work, or additional visits to their doctor (Forster, Muff, Peterson, Gandhi, & Bates, 2003). Frailty puts older adults at risk for problems after hospital discharge. When frailty is combined with the effects of hospitalization new or worsened problems with physical functioning often occur.

Frailty

When older adults are hospitalized they are at increased risk for developing new problems that are unrelated to their reason for hospitalization. These problems are generalized body weakness specifically related to bedrest and reduced mobility during hospitalization (Brown, Friedkin, & Inouye, 2004), which often results in increased risk for acute confusion, incontinence, and falls (Creditor, 1993; Wakefield, 2002). The risks of problems continuing after discharge from the hospital are only increased when older adults were physically frail prior to hospitalization.

Physical frailty. Physical frailty may be conceptualized as a pathological condition that leads to physical impairment, functional limitations, and disability, which in turn leads to increased vulnerability to disease and disability (Leville, Fried, McMullen, & Guralnick, 2004). Initially, the physical changes associated with frailty may be very slight, but when disease and functional limitations can no longer be accommodated, the signs of frailty become more overt (Ferrucci et al., 2004). The initial changes that precede the development of musculoskeletal and strength changes associated with frailty are subtle and include reduced sensory abilities, reduced nutrition, reduced lean body mass, poor endurance, reduced activity, and impaired cognition (Fried et al., 2001; Schuurmans, Steverink, Lindenberg, Frieswijk, & Slaets, 2004). However, the musculoskeletal and strength changes associated with frailty are more obvious and include problems such as muscular weakness (Bortz, 2002), reduction in static and dynamic balance, decreased strength, decreased range of motion, decreased gait speed, decreased aerobic capacity (Brown, Sinacore, & Kohrt, 2000), decline in mobility, and reduced overall physical fitness (Callen, Mahoney, Well, Enloe, & Hughes, 2004).

Fried, Ferruci, Darer, & Anderson (2004) have done extensive work to identify the characteristics of physical frailty. The phenotype for frailty included the presence of three or more of the following characteristics: (a) shrinkage, defined as unintended weight loss; (b) weakness, measured by grip strength; (c) poor endurance, defined as self-reported exhaustion; (d) slowness (time to walk 15 feet); and (e) slow physical activity, defined as how many kilocalories are expended. In the frailty phenotype study undertaken by Fried et al., frailty remained an independent predictor for falls, hospitalization, disability, and death. This relationship remained even after adjusting for socioeconomic status, health status, subclinical and clinical disease, depression, and disability at baseline. Other studies have consistently defined frailty in terms of functional ability with interventions aimed at reducing functional losses and disability (Binder et al., 2004; Gill, Hardy, & Williams, 2002; Gill & Kurland, 2003).

The North American Nursing Diagnosis Association (NANDA) has not identified frailty as a distinct nursing diagnosis. However, features of frailty can be identified within the nursing diagnoses of activity intolerance, fatigue, impaired physical mobility, chronic confusion, impaired memory, and nutrition less than body requirements. Scientists unanimously agree that frailty exists but are not in agreement about how to define it. Frailty has been defined in numerous ways such as poor physical health, poor mental health, disability, mobility impairment, or dependency (Brown, Renwick, & Raphael, 1995). This lack of agreement about definition may make it difficult to identify frailty as a distinct physical and/or social condition in either the Nursing Intervention Classification (NIC) (McCloskey & Bulechek, 1996) or Nursing Outcomes Classification (NOC) (Johnson & Maas, 1997).

There have been numerous attempts to identify predictors of physical frailty. Brody, Johnson, and Ried (1997) identified age, bathing assistance, medication assistance, and health conditions that interfered with daily activities as being predictive of developing frailty. Later work by Brody, Johnson, Ried, Carder, and Perrin (2002) added predictors such as the need for dressing assistance, eating assistance, and help with money management. Still others have identified people who have problems performing activities of daily living (ADL) and who have a substantial degree of disability as frail (Guralnik & Simonsick, 1993; Nourhashemi et al., 2001).

Contribution of cognitive changes to frailty. The frailty phenotype as a measure of physical frailty works reasonably well to identify the physical features of this poorly defined condition. However, what the phenotype fails to do is to include other conditions that may contribute to the development of frailty. Cognitive loss is one such condition. Verbrugge and Jette (1994) assert that physical and mental abilities are not discrete concepts but work in concert. The relationship between the two concepts is not constant or unidirectional. Impaired cognitive abilities impact thinking activities that are required to successfully function; the inverse relationship is not true. Impaired physical functioning does not necessarily impact thinking ability or intellect.

Nonetheless, within the context of loss of physical ability in the frail elderly, cognitive deficits are often precursors to loss of function. It has proven to be very difficult to objectively identify skills lost due to cognitive deficits. Lowenstein et al. (2001) found that caregivers of older adults with mild to moderate Alzheimer’s dementia tended to overestimate their family member’s ability to function with day-to-day tasks that relied on adequate cognition, such as telling time, identifying currency, and using eating utensils. As the condition worsened, children who did not live with parents consistently overestimated their parent's abilities to live independently without assistance.

Nevertheless, many researchers view frailty primarily associated with cognitive losses as a distinct clinical entity different than physical frailty (Ferrucci et al., 2004). This viewpoint is supported by the DSM-IV criteria, which is used to identify criteria for the diagnosis of psychiatric illness. The DSM-IV does not include frailty in the criteria, but does include dementia by all causes. Thus it can be assumed that frailty is not viewed as a psychological problem per se, but as a manifestation of dementia. Regardless of why ability is lost, whether through physical changes or lack of memory of how to perform the task, the result is the same: loss of a fundamental skill.

Social elements of frailty. What becomes confusing about the plethora of literature on frailty are the inconsistent definitions and predictors that operate more like identifying characteristics of frailty as a syndrome, but fail to address the social elements of frailty. The social models of frailty are based on the notion that frailty is a physical problem that plays out within a community of people. Kaufman (1994) contended that frailty was socially produced through interactions between older people, their caregivers, and their health care providers. Frailty only becomes a problem when the scale of adaptation is tipped toward dependence in functional abilities and social role function. From a social perspective, frailty occurs when an individual has reduced ability to carry out practical and social activities of daily living (Brown Renwick, & Raphael, 1995).

Placing frailty in context. Historically, frailty has been so poorly defined that it has become a synonym for disability or an outcome of poor physical health (Gillick, 2001).

Overall, frailty has become a general marker for poor outcomes in the elderly (Thomas, 2002), particularly if general decline is accompanied by a diminished ability to carry out important activities of daily life, including social functioning (Brown, Renwick, & Raphael, 1995; Kaufman, 1994). Frailty certainly has the potential to impact physical functioning and to influence the choice of discharge destination after hospitalization.

At the present time there are approximately 6 million frail older adults in the United States (Bortz, 2002). It is alarming to realize that the caregivers of older adults tend to be as old or older than and nearly as frail as the elder family member for whom they are giving care. Caregivers themselves often engage in risky health behavior and have multiple medical conditions, vision and hearing impairments, and diabetes (Burton et al., 2003; Desbiens, Mueller-Rizner, Virnig, & Lynn, 2001). Thus, the caregiver and care recipient may both be at significant risk for institutionalization should changes occur in the health status of either person. When frail adults are hospitalized, there is always the potential that they will not be able to return home to live their lives as they had previously.

When older adults are frail, and family members are equally old, or are not present in the same community, decisions about hospital discharge destination become challenging. Older adults value the ability to live independently at home. Irrespective of others questioning the wisdom and safety of having the older adult return home after hospital discharge, it remains the goal for the older adult.

Hospitalization

Hospitalization places older adults at significant risk for functional limitations and difficulty remaining independent in the community (Creditor, 1993; Sager et al., 1996).

When frail older adults are hospitalized, they are not only at risk for worsening health and functional status, but they often live alone and face significant challenges in returning home. As identified in the previous chapter, frail older adults are hospitalized more often than younger adults. While it is tempting to blame simple old age for the diseases and health care challenges present in the elderly, what really defines old age is more complex than a time line of years lived.

Those who are aging socially construct the experience by interpreting and discerning for themselves what it is like to grow old (Gubrium & Holstein, 2000). Although there is an increased incidence of disease in older adults, chronological age and physiologic age do not always coincide. The very old often enjoy robust health, while the younger old may be challenged by chronic health conditions and functional impairments. Nonetheless, the aging body is more prone to illness and disease. Diseases such as osteoporosis, osteoarthritis, and temporal arteritis occur more often in the elderly and are due to the effect of the degenerative changes in the body that occur with old age (Timiras, 2003). Other diseases such as pneumonia, septicemia, cirrhosis, nephritis, cerebrovascular disease, heart disease, hypertension, emphysema, neoplasm, Alzheimer’s disease, and Parkinson’s disease occur more often in the elderly but are not primarily due to aging (Timiras, 2003).

Ultimately, when people who are ill can no longer take care of their illness at home they are hospitalized. Hospitalization places frail older adults at risk for developing serious complications that can be attributed directly to being in the hospital. Many frail older adults who enter the hospital leave more impaired than when they came in as a result of the combined effects of illness and hospital routines (Creditor, 1993). The complications of hospitalization include acute confusion, falls, urinary incontinence, reduced muscle strength, and weight loss (Creditor, 1993). Brown et al. (2004) identified that as many as 16%-33% of hospitalized frail older adults may be placed on complete bedrest for prolonged periods of time without valid medical reasons. The indiscriminant use of bedrest may lead to an undesirable loss in functional abilities. Sager et al. (1996) reported that 32% of patients in their study declined in ADL function and 40% declined in IADL function during hospitalization. Those who had changes in ADL or IADL function associated with hospitalization were significantly more likely to be rehospitalized or admitted to a nursing home to live within 3 months of hospital discharge.

Discharge Planning

One recognized protection against rehospitalization and unplanned nursing home admission is adequate discharge planning that effectively utilizes community resources (Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Hyde, Robert, & Sinclair, 2000). Nevertheless, discharge planning continues to be an inflexible, poorly defined process that does not fully address the effects of physical illness, loss of functional ability, the effects of depression, delirium, or the challenges of learning new routines as a result of illness and hospitalization (Bowles, Foust, & Naylor, 2003; Naylor, et al., 2004; Oktay, et al., 1992). Furthermore, when discharge plans were reviewed, the plans were found to underestimate what frail older adults and their families need to do to successfully live at home (Proctor, Morrow-Howell, & Kaplan, 1996).

Home health care. Home health care is a service that is ordered to help older adults at home after hospital discharge as they continue to recover from their illness. One study found that clinicians failed to refer up to 26% of patients for home care who would have benefited, and females were less likely to be referred than were males for home care services (Bowles, Naylor, & Foust, 2002). Often, only those patients with obvious self-care problems were referred for home health care. Those referred included patients who were older, frail, had longer hospital stays, or who had worse functional assessment scores (Bowles et al., 2002). In another study, when hospital personnel planned to discharge a patient, they did not routinely measure actual physical functioning; rather decisions were made based on staff perceptions of physical functioning (Bowles, Faust, & Naylor, 2003). Findings are equivocal about whether nurses overestimate or underestimate physical functioning (Morrow-Howell, Proctor, & Mui, 1991; Reiley et al., 1996). Nonetheless, when hospital discharges are not based on accurate data, frail older adults are placed at risk for significant problems after discharge home.

Needs assessment. It is essential that health care teams members (HCTM) focus less on medical diagnosis and address areas equally cogent, to successful discharge planning such as family social issues, problems with understanding home treatments including medications, and the overall impact of chronic conditions on daily life (Bowles et al., 2003). Successful discharge planning for frail older adults hinges on the health care team’s understanding of the home situation. However, the factors commonly used by the HCTM in the hospital to assess the home situation may not adequately address home care needs. Hospital HCTMs were found to assess factors such as indicators about severity of illness, length of hospital stay, and inappropriate days of stay (Mamon et al., 1992). One factor that was commonly disregarded was identification of how the older adult would function at home with or without family assistance and support. Even when discharge was planned reasonably well, frail older adults were often discharged to their home with serious problems. Peng, Navaie-Waliser, and Feldman (2003) found that one-third of all patients in their study had anxiety and confusion; one-fifth had poor cognitive functioning or depression present at the time of discharge.

Lack of services. Over 15% of older adults have been found to have no formal or informal services available at the time of discharge (Peng, Navie-Waliser, Feldman, 2003). This finding is extremely concerning given that older adults who would potentially have benefited from home health services or nursing home admission may not have had their situations adequately assessed while still hospitalized so that actions could have been taken to mitigate the possible problems associated with being discharged to their homes. The risk factors for nursing home admission have been well documented and included living alone, functional limitations, lack of caregiver availability, lack of emotional support, or need for extensive support to remain independent in ADLs or IADLs (Callen et al., 2004; Espejo, Goudie, & Turpin, 1999; Weaver & Bryant, 1990).

The discharge planning process, including decisions about services and placement are often inadequate to meet the ongoing care needs of older adults. Problems with discharge did not lie entirely with the health care team. Family and friends may agree to participate in ongoing home care while the older adult is still hospitalized, but find that they are unable to fulfill that agreement once the older adult is discharged home. Proctor, Morrow-Howell, and Kaplan (1996) found that 40% of discharge plans had one or more components that were not implemented as planned. One such discrepancy included not receiving care from family or friends as arranged. Over 76% of older adults discharged from the hospital did not have their needs anticipated by the discharge planner. This underestimation of need after discharge occurred as (a) a result of poor communication between the older adult and the HCTM, or (b) failure of the older adult to describe accurately to the HCTM their needs or problems because of their desire to return to their own home, even if living alone may be difficult.

Effect of Physical Functioning on Discharge Destination Decisions

Functional limitations. Limitations in performing fundamental physical or mental activities used in daily life by one's age-sex group are called functional limitations (Verbrugge & Jette, 1994). Fundamental physical activity involves balance, gait, overall strength and mobility of both upper and lower extremities, hearing and vision, and mental activities (Jette, Assman, Rooks, Harris, & Crawford, 1998; Verbrugge & Jette, 1994). Examples of physical activities include walking, lifting objects, climbing stairs, hearing, and reading. Mental activities are different and involve abilities such as remaining alert, adequacy of short and long-term memory, and orientation to the environment and time (Verbrugge & Jett). Activities referred to overall ability of the body and mind to do purposeful work and were the basic interface between the person and the physical and social milieu in which they routinely functioned (Verbrugge & Jette).

Disability. Whereas functional limitations are the actual limitations in performance of activities, disabilities are the gap between individual capability and situational demand. Thus, either decreasing demand or increasing personal capability can reduce disability (Verbrugge & Jette, 1994). Verbrugge and Jette (1994) contend that current measures of functional ability measure intrinsic ability only, which is the ability to perform a task without assistance from people, environment, or equipment. Whereas actual ability measures what people are able to accomplish using supports such as people, environment, or devices. If only intrinsic ability is measured, then actual disability may be overstated. Thus, people who use resources to reduce the impact of disability may appear more disabled than they actually are when only intrinsic ability is measured.

Conceptual problems. The terms frailty, functional limitation, and disability are often used interchangeably or in conjunction with one another in the literature (Bortz, 2002). This mixing of concepts leads to lack of conceptual clarity in measurement. It is not uncommon for both functional limitations and disability to be measured using activities of daily living (ADL), which are abilities to eat, toilet, get in and out of a bed, or chair (transfer), dress, and bathe, or by using instrumental activities of daily living (IADL), which are the abilities to prepare one's own meals, do light housework, manage money, use the telephone, and shop for personal items. Other things may also be included in IADLs, such as doing lawn care, hobbies, and leisure activities (Verbrugge & Jette, 1994).

In an effort to reduce the confusion about conceptual differences between functional limitation and disability, Verbrugge and Jette (1994) referred to differences between what one was capable of doing and what one actually did as being the key factor to use in differentiating between the two concepts. Using this framework functional limitations refer to individual capability without regard to situational requirements, whereas, disability refer to difficulty that is experienced while doing activities using supports (both devices and people) in any domain of one's life (Verbrugge & Jette, 1994).

Problems with measurement. Conceptual problems have subsequently led to problems with measurement. There is a mismatch between what is measured by classic instruments such as the Katz ADL scale, which measures independence in ADL, and how scholars use the instruments in research to measure negative constructs such as functional disability, functional impairment, and functional limitations (Porter, 1994). This issue raises questions about validity when instruments which are designed to measure independence in functioning are conceptualized in the negative and used to measure impairments or limitations in functioning. Porter recognized that circular logic was in place when measurement of independence in ADL was assumed to measure a construct such as impairment and then was used to address possible indicators of ability to be independent.

Validity of measurement. Measurement of limitations has been made more challenging by the very nature of functional change in the frail elderly. Early limitations in functional abilities often develop in a subtle manner, with changes first occurring in how older adults perform activities so that essential functional abilities are preserved. These changes are identified as preclinical changes in functioning that most often affect frail older women and are generally mobility problems that precede the development of actual clinical impairment and disability (Fried, Bandeen-Rhoche, Chaves, & Johnson, 2000; Whetstone et al, 2001).

Functional abilities are not lost in a linear fashion but are often lost in clusters, which simply mean that problems in one area of functioning, such as reaching, impacts other areas such as lifting or stooping. There is significant overlap in upper and lower body functioning; changes or weakness in the upper body also affect lower body functioning. However, current measures often artificially separate upper body function from lower body function even though the human body works in concert (Long & Pavalko, 2004).

Losses of ADL and IADL function are known to occur in a hierarchical progression with changes first occurring in mobility, followed by IADL and ADL (Whetstone et al.). The hierarchical model of loss is supported in the frailty phenotype study; Fried et al. (2001) found that 72% of older adult women reported difficulty in mobility and 60% reported difficulty in IADLs, while only 27% reported ADL difficulty.

To obscure matters further, there are also concerns about the validity of self-reported ADLs and IADLs, which may only measure frail older adults' reported perceptions of their functioning (Sayers et al., 2004). To combat this problem, some investigators encourage the use of "think aloud protocols" to help capture the extent of difficulty frail older adults may have had with performing ADLs and IADLs (Keller, Kovar, Jobe, & Branch, 1993). Think aloud protocols are typically used to evaluate the specific wording of questions to determine whether or not the respondent clearly understood the questions and was able to answer those (Singleton & Straits, 2001, p. 63).

Keller et al. (1993) used "think aloud protocols" to determine whether the meaning of words and phrases used in functional status questionnaires had the same meaning for the respondents as for the questionnaire designers. They also wanted to identify whether or not respondents remembered the extent of human assistance they used. Over half of the respondents who denied receiving help because of a health or physical problem subsequently acknowledged that they did have a physical problem that required help. There was also a variation in dependence not addressed by the instrument. For example, the respondents did not need help all the time, but only when external circumstances that worsened their ability to function existed, such as weather changes that made it difficult to leave the house. This led the investigators to conclude that all questions about functioning should be tested using cognitive methods on samples of participants to whom the questions apply so that subtle nuances in how respondents framed their answers could be identified (Keller et al.). If this approach were used more consistently in instrument development, perhaps it would be possible to develop instruments that phrase questions in such a way as to make them clearer to respondents.

Limitations of physical measurement. Kaufman (1994) identified that the artificial dichotomy of independence and dependence created an adversarial approach to care and did not actualize the value of interdependence, community, and cooperation. When older adults were faced with new or worsening debility, health care team members did not consistently identify the strengths of the community. Nor were the identified strengths used to develop workable plans for living in the community. This lack of awareness often led older adults to reject the solutions that did not fit well in their lives. Thus, older adults ran the risk of being labeled by the health care community as noncompliant or difficult (Kaufman, 1994; Patterson, 2001).

Raphael et al. (1995) took the discussion a step further by identifying that frailty was a result of the intersection of personal ability, available support, and other relevant aspects of the older adult’s life situation. These views brought the discussion of functional measures, frailty, physical functioning, and disability full circle; functional decline did not necessarily become frailty or become a disability if older adults were able to garner the necessary supports. The current operational definition of functional ability may be too limited, because it appears that health care teams often fail to assess how older adults use pivotal community and family relationships in their daily lives to buffer against the development of disability.

In her phenomenological study about older widows, Porter (1994) identified the extent to which an artificial dichotomy has evolved between independence and dependence. Porter discovered that elderly widows reported how they performed ADLs in a way that was unique to each individual's ability and desire to sustain themselves in their personal environment. Independence with ADLs and IADLs for frail older widows was considered by them to be within the context of creating their own schedule and deciding how to accomplish tasks (including having someone else do it) so that they remained active in their community (Porter).

This is similar to how Gubrium, Rittman, Williams, Young, and Bolysten (2003) described how stroke survivors used resources such as people or equipment to handle the challenges of everyday life and benchmarked their progress in stroke recovery. Similarly, Gubrium et al. 2003) and Porter (1995) identified that help in the form of people or devices were inherent in how frail older adults functioned in their everyday lives. Thus, it would make sense for discharge planners to look at how older adults use people, equipment, or environments as supports in their daily life and not limit assessment to intrinsic ability, thereby reducing the possibility of understating either the strengths or problems of the older adult.

Physical symptom and function. Disability, frailty, and functional limitation are conceptualized as related clinical syndromes (Fried, Ferruci, Darer, Williamson, & Anderson, 2004; Phelan, Williams, Penninx, Loferfo, & Leville, 2004) often diagnosed by self-reported difficulty, but also by objective performance-based tests of function in self-care tasks (Fried et al., 2004.) Disability can develop both slowly and chronically, or acutely and catastrophically. The effects of disability often include other clinical issues such as pain, endurance, balance, and mobility problems. It is interesting to note that medical problems associated with pain, endurance, and mobility also reduce functional abilities in ADLs and IADLs.

Thus, it can be seen that clinical problems and symptoms can be both the cause and the result of disability. This circular process of symptoms worsening functioning was demonstrated in a women's health study. Leveille, Fried, McMullen, and Guralnik (2004) found that in osteoarthritis, pain was the common symptom of the arthritis, but also the cause of disability. Women did not continue to do their ADLs or IADLs because of pain. Likewise, in women with chronic lung disease, lack of endurance was both a symptom of their illness and also the cause of their disability.

Functional loss and disability are very dynamic processes in the frail older adult. It is valuable to remember that physical functioning does improve, even in frail older adults (Guralnik & Simonsick, 1993). An integrative review of national surveys about demographic trends of disability indicated that the prevalence of any disability has declined by –1.55% to –0.92% per year between 1980 and 1990. However, the reductions did not hold across all categories of disability. Late-life disability decline concentrated in the area of IADLs. These findings were not consistent for ADLs with only one National Health Interview Survey showing reductions in ADL ability (Freedman, Martin, & Schoeni, 2002).

Social elements of physical functioning. The social world of the frail older adult is intrinsic to how they function day to day. However, the use of the social world to support independence creates a problem in measuring ADL and IADL as long as traditional instruments of functioning continue to be the most common way for health care providers to measure disability and functioning at home (Leveille et al, 2004). Measurement of disability is variable and multifarious because of the lack of agreement about how to incorporate concepts such as (a) availability of help with ADLs and IADLs and (b) the willingness of the frail older adult to continue to do the task either with or without help even if they could do it independently (Bootsma-van der wiel et al., 2001). When help is given to and accepted by older adults before it is necessary, lowered activity levels result, which consequently lead to reductions in activity that contribute to the continued development and worsening of mobility and chronic health conditions (Fried et al., 2004). Thus, independence is not measured by lack of difficulty in performance of daily tasks of daily life, but by how older adults use their social world and their supports to retain and improve independence in ADLs and IADLs for as long as possible.

Models of disability. The continuum of disability is described as lack of difficulty in functioning on one end, to total dependence in functioning on the other end (Gill, Robison, & Tinnetti, 1998). There are models of disability that incorporated both the physical and social elements inherent in the development of disability. The model of disability originally developed by Nagi (1979, 1991) and adapted by the Institute of Medicine begins with pathology, which leads to the development of impairment and functional limitation. Ultimately, disability resulted when there was a limitation in performance of socially defined roles and tasks within a sociocultural and physical environment.

Verbrugge and Jette (1994) further developed Nagi's model when they added crucial individual and social factors. The main pathway originally identified by Nagi remained intact, but social elements that enhanced the explanatory power of the model were added.

These added social factors included: (a) risk factors, which are characteristics that predispose to disability, demographic characteristics, lifestyle, social, behavioral, environmental, and biological factors; (b) extra-individual factors, such as medical care, rehabilitation, medications, external supports, and physical and social environments; and (c) intra-individual factors, which include lifestyle, behavior, psychosocial attributes, and activity accommodations.

Thus, functional limitations become disability when limitations interfere with frail older adults' ability to care for themselves in their social environment using their usual supports (Verbrugge & Jette, 1994). Disability, when seen as a gap between personal capacity and environmental demand, may be the reason that frail older adults are unable to return to their previous living situation after hospitalization (Verbrugge & Jette). A change from informal to formal care is often required if older adults are not able to bridge the gap between their intrinsic ability and situational demands. Families have historically been and continue to be the main source of informal care. If families cannot supply the needed help or support, the likelihood of having to move to formal care services is greater. If older adults and family members cannot reach congruence about how much and what type of care will be given at home, the likelihood of problems related to living at home increase.

Informal Caregiving

There are over 22.4 million households involved in caregiving nationwide (National Alliance for Caregiving and American Association of Retired Persons, 1997). For many frail older adults, family members are the actual and preferred source of care and support (Noonan, Tennstedt, & Rebelsky, 1996). There are different types of caregiving support offered by family members of frail older adults. Aberg, Sidenvall, Hepworth, and O'Reilly (2004) identified three caregiving situations: (a) social-emotional, which is characterized by simply maintaining contact; (b) proxy support involves checking on, planning, arranging, and managing the household and medical care; and (c) instrumental caregiving, which is assisting with or doing household tasks.

Family caregiving. Caron and Bowers (2003) referred to shifting caregiving transitions from interrelational caregiving (giving support) to pragmatic caregiving (giving care). The type of care given by family members was often determined by the caregiver's relationship with the frail older adult and by family orientation, either individualist or collectivist (Pyke, 2002). Families with an individualist orientation minimized caregiving, provided less informal support, and relied more on formal support than families with a collectivist orientation (Pyke & Bengston, 1996). Older adults without children or living children offered special challenges because children are often the care providers for frail older women (Katz, Kabeto, & Langa, 2000). Kane, Renardy, Penrod, and Huck (1999) found that 28% of care after hospitalization was given by a spouse, 48% by an adult child or children, 21% by a relative other than child, and 3% by a non-relative. However, disabled men (43.8%) were more likely to have received care from their spouse than were disabled women (11.1%). Overall, children played a more dominant role in caring for disabled women than men. Over 44.6% of women and 22.8% of men reported assistance by a child.

Other individual factors that influence family care include the care provider's physical health (Allen & Ciambrone, 2003; Ladkita & Laditka, 2001) and competing demands such as employment and geographic distance (Allen & Ciambrone). Caregivers for frail older adults are often spouses who have lower incomes and poorer health (Burton et al., 2003). White male caregivers, particularly spousal caregivers, are more likely than female caregivers to have received formal assistance with the care of a family member (Miller & Guo, 2000). Katz et al. (2000) found that among older adults with one to two ADL or IADL impairments, 27.2% of women and 48.6% of men received informal care, and on average women received less care per week (10.0 hours/week) than men (19.6 hours/week).

Caregiver strain. Caregiver strain is associated with limited secondary support from either formal or informal sources (Mui, 1995). Caregiver strain occurs when there is limited ability to provide care because of competing employment, family responsibilities, poor health of the caregiver, or geographic distance (Allen & Ciamborne, 2003). There are increased symptoms of depression, poorer self-rated health, and high-risk health behaviors when, caregivers for older adults transition to heavy caregiving responsibilities (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003). Those who were caregivers for people with dementia reported greater burden when the care recipient had behavior problems (Chappell & Reid, 2002). If the care provider was an adult child, there was less perceived burden associated with providing care than if the care provider was an extended family member or non-family member (Call, Finch, Huck, & Kane, 2005).

Male and female caregivers. Mui (1995) found that men and women found different aspects of caregiving to be stressful. Women reported greater emotional and physical strain than men. However, men reported more overall difficulty transitioning to the caregiver role. One explanation for this difference may have been that men were more likely to receive emotional support from their adult children and practical assistance from formal agencies (Miller & Guo, 2000). Women had a greater number of social contacts, but less practical assistance. Thus, men's transition to caregiving may have been buffered by the degree of practical support they received (Miller & Guo). The transition from hospital to home is particularly difficult for older adults who faced the dilemma of insufficient caregiving resources at home (Naylor & Shaid, 1991).

Reactions to caregiver stress. Significant problems result from lack of attention to caregiving stress. In a study to identify potentially harmful behavior, Beach et al. (2005) found that 26% of care recipients reported being subjected to potentially harmful behavior by their informal care providers. Verbal interactions included use of harsh tone of voice, swearing, yelling, or name-calling. Physical interactions included behavior such as hitting, slapping, shaking, or roughly handling. The investigators concluded that potentially harmful behavior was more likely in caregiving situations where care recipients required more care, and the care provider was cognitively impaired and had symptoms of physical illness, or depression.

Caregiver stress may decrease congruence about discharge destination decisions. When family members are stressed and no longer about able to adjust to caregiving demand, it may become more likely for them to desire a different caregiving situation for the older adult.

Spouse as caregiver. Spouses were the first, and often the only source of caregiver assistance to frail older adults (Tennstedt, 1999). Spouses who are at risk of becoming a caregiver are often older, have lower incomes, lower sense of self-mastery, and more health risk behaviors (Burton et al., 2003). Behavioral problems of the older adult care recipient, not the physical care provided were directly related to stress, poorer sense of well-being, and increased sense of caregiver burden (Chappell & Reid, 2002). Wives in particular found behaviors such as repeated questions, clinging to the caregiver, and swearing troublesome (Ingersoll-Dayton & Raschick, 2004). The major concern for spousal caregiving revolves around the issue of frail older adults giving care to their frailer spouse. Older spouse caregivers who had poorer subjective health were more likely to place their spouse in an institution when caregiving demand increased and resources declined (Guaguler et al., 2003). Women who were disabled often were the primary caregivers for their disabled spouses (Katz et al., 2000). If other family caregivers such as children, fictive kin, or extended family were not available or willing to help then institutionalization became more likely.

Children as caregivers. If the caregiver was an adult child, findings are equivocal as to who gave more care to parents, sons or daughters. According Laditaka and Laditaka (2001) daughters (53%) and sons (28%) who were not in a couple were substantially more likely to help than were sons in a couple. Daughters tended to help more hours, and in particular African American daughters helped substantially more hours than Caucasian daughters. Children were not the only sources of informal support. Support also came from extended family, such as nieces, nephews, and grandchildren (Forbes, Hoffart, & Redford, 1997) and other informal caregivers, such as neighbors or friends (Proctor, Wilcockson, Pearson, & Allgar, 2001). Nonetheless, 15% of frail elders had no formal or informal support (Peng et al., 2003). These frail older adults were at significant risk for placement in a nursing facility at the time of hospital discharge.

Ethnic differences. There are ethnic differences in caregiving patterns. The United States has historically been described as a melting pot of different ethnic groups. The myth of the melting pot encouraged all ethnic groups immigrating to the United States to assume the predominant values of the American culture in order to succeed in the new society (Friedman, Bowden, & Jones, 2003, p. 215). However, homogenization of society is no longer valued as it once was. There is currently an evolving recognition that cultural diversity within our society is positive. Cultural diversity may enrich family life, strengthen the bonds of intergenerational continuity, and support open communication with people from other ethnic groups (Friedman et al., p. 216). Diversity inherently implies different worldviews and views about the meaning of home.

Meaning of home. Home not only denotes a place or dwelling, but also has a multitude of emotional meanings that will vary within and between ethnic groups. The home environment is both a physical dwelling and also has a meaningful context for daily life (Kontos, 1998). The meaning of home differs based on ethnic background. Home is not only a place, but is also a space where activities and relationships are played out daily (Mallett, 2004). For frail older adults, home was often identified by respondents as the place they did not want to leave, even though they may not be safely able to remain there because of neighborhood violence or poor living conditions (Johnson, Radina, & Popejoy).

Family orientation. Ethnic groups such as African Americans and Latinos are defined by a strong collectivist orientation to family relationships (Johnson, Schwiebert, Alvardo-Rosenmann, Pecka, & Shirk, 1997). For those groups, leaving home to be admitted to institutional care in a nursing home may not be an acceptable option. The actual and preferred informal care networks for both Latinos and African Americans are family members (Johnson & Tripp-Reimer, 2001). Additionally, African Americans include non-family members or fictive kin in their informal care networks (Johnson & Tripp-Reimer).

There is some question as to whether ethnicity or socioeconomic status and education most influences placement in an institutional setting (Weiss, Gonzalez, Kabeto, & Lango, 2005). Sudha and Mutran (1999) identified that high socioecomonic status and having past experience with institutional care reduces concerns about institutional placement for both African Americans and Caucasians. Furthermore, a stated preference for family care did not necessarily mean that institutional placement was seen as an unacceptable option. They also found that African Americans expressed a greater preference for family care, yet disliked nursing homes less than Caucasians.

Informal care networks. Informal care networks between African Americans, Mexican Americans, and Caucasians differ in several ways (Feld, Dunkle, & Schroepfer, 2004). African Americans are 62% less likely than whites and 87% less likely than Mexican Americans to rely solely on spouses for informal support (Feld et al.). Frail older adults of all ethnic groups use a combination of formal and informal sources of care. Weiss, Gonzalez, Kabeto, and Langa (2005) found that Latinos (44.3%) were more likely to receive informal care than were African Americans (33.9%) or Caucasians (24.6%). Latinos also received help for more hours than did Caucasians, and African Americans, (11.0 vs 6.3 vs 7.5 week hours, respectively) (Weiss, Gonzalex, Kabeto, & Langa). These data contrast with findings by Feld et al. (2004) that showed unmarried Mexican Americans were significantly less likely than African Americans or Caucasians to use informal sources of help. Solely informal networks of help were 74% less likely to have occurred for Mexican Americans when compared with Caucasian elders, and 83%

less likely to have occurred when compared with African American elders. However, these study findings must be interpreted cautiously because of the small sample size.

African Americans were more likely to share informal caregiving responsibilities than were Mexican Americans and Caucasians (Navie-Waliser et al., 2001). Living arrangements and prior relationships may have played a significant role in the extent of informal care received, regardless of ethnic origin (Burton et al., 1995). There has been an overriding assumption that Mexican Americans lived with their families, but Weiss et al., found that 28% of Latino elders lived alone. None of the studies addressed the impact of new immigration on family structure, nor did they address differences within groups. Only Weiss et al. (2005) talked about the differences between subsets of Latinos (Mexican American, Cuban, Puerto Rican) as they pertained to U.S. citizenship, employment, access to insurance, and income.

For many Mexican Americans informal caregiving may have been viewed positively as self-sacrificing, devoted, and protective (Lim et al., 1996). Feld et al. (2004) found that African Americans were more likely than Caucasian caregivers to endorse communal caregiving, which was in keeping with the African American collectivist view of family. Caucasian female caregivers had the largest social network of assistance and white males the greatest degree of practical assistance from informal and formal sources (Marcantono et al., 1999). Nevertheless, most caregivers did not receive formal support, even when the caregiving burden was substantial, which placed the caregiver at risk for problems associated with the caregiving activity (Navie-Waliser et al., 2002). In a large national sample, 36% of all caregivers surveyed were identified as vulnerable, meaning they had fair to poor health and at least one serious health condition (Navie-Waliser, et al.).

When caregivers themselves are frail or in poor health decisions about discharge destination may only become more critical and more difficult to make.

Formal Caregiving

Formal community care included home health care, personal care services, or nursing home care. Home health care was often underutilized, with clinicians failing to refer 26% of hospitalized patients who would have benefited from home health care (Bowles, Naylor, & Foust, 2002). However there were problems with the type and extent of home health care services available, as well as accessibility of services across geographic regions (Tennstedt, 1999). Over 1.7 million Americans receive home health care services annually (Advance Data 309, 1996). The majority of clients who receive home health services were elderly widowed Caucasian females who live in private residences (Advance Data 309, 1996). Eighty-five percent of men and 84% of women who were admitted to home health care receive skilled nursing care services (Advance Data 309, 1996).

Paying for care. The Medicare Home Health Care benefit is very limited in the scope of services offered. Medicare will not cover personal care services after older adults are discharged from Home Health Care. Personal care services must be paid either privately or by the Medicaid Waiver programs. However, to be eligible for personal care services under waivered programs, the individual must be Medicaid eligible and also meet the required nursing home care level of care (Leblanc, Tonner, & Harrington, 2001). Personal care services are very challenging for older adults to pay for because these services are expensive. Thus, older adults must either be impoverished to receive assistance from Medicaid or be financially well off enough to pay privately for personal care services.

The challenge of finding formal sources of community help and the cost of the help may offer another explanation as to why informal care from family continues to be the predominant way that older adults receive personal care support. As informal care needs increased either in intensity or amount, the system of care often became difficult for the family to maintain. For some older adults and their families, community care became a transition to formal care services, such as nursing home admission (Gaugler et al., 2003). Family members of frail older adults may find that it increasingly difficult to achieve congruence about hospital discharge destination decisions when the informal care system is no longer functioning well.

Nursing home admission. Frail older adults may initially be admitted to a nursing home in one of two ways, either from home or from the hospital. Morrow-Howell and Proctor (1994) found those who were most physically dependent were most likely to be discharged to the nursing home from the hospital. Nursing home placement may have either been a temporary decision related to the need to receive further rehabilitation for an injury, or a permanent decision because of declining health and increased care needs (Bernstein et al., 2003). The number of hospitalized older adults admitted to nursing homes has been steadily climbing since 1985, when 12.4% were admitted to the nursing home from the hospital. In the year 2000, 19% of adults age 65 or older discharged from the hospital were admitted to a nursing home (Bernstein et al., 2003). The decision about nursing home admission was often contingent on adequacy of formal and informal care systems in place in the home prior to hospital admission (Gaugler et al. 2003).

Past research as shown that frail older adults who lived at home were more at risk of having to move to a nursing home for care if they lived alone (Weaver & Bryant, 1990), were in poor physical health (Ryan & Scullion, 2000), had functional limitations (Gaugler et al., 2003), or had dementia (Gaugler et al.). The decision to move to a nursing home was a difficult yet practical one for many frail older adults and their family members (Caron & Bowers, 2003; Espejo, Goudie, & Turpin, 1998). HCTMs, particularly physicians often decided that admission to the nursing home was necessary and informed the frail older adult and their family about the need for admission (Forbes, Hoffart, & Redford, 1997; Johnson, Schwiebert, & Rosenmann, 1994). This recommendation by the physician was often accompanied by the frail older adult's recognition that they could not make it alone (Forbes et al, 1997).

In other research social workers viewed sending patients to a nursing home more favorably than sending patients home, because they were concerned about the ability of the caregiver network to meet the patients' needs (Morrow-Howell, Proctor, & Mui, 1991). Nonetheless, the need to place a frail older adult in a nursing home was most often identified by the family member who provided the bulk of the care (Gaugler et al., 2003). Frail older adults who had more cognitive or functional impairment and had private pay resources or Medicaid were more likely to be admitted to a nursing home than those without adequate monetary resources or Medicaid (Morrow-Howell & Proctor, 1994). There is the possibility that not all family members will agree with a plan for placement. There is a need to understand more about the process used by frail older adults, family members, and HCTMs to achieve decisional congruence.

Conclusion

Hospitalization was a stressful event for frail older adults and their family members. Not only is hospitalization stressful, but also it was fraught with potentially dangerous problems such as delirium, injuries related to falls, new incontinence, infections, and profound weakness (Chang, Chenoweth, & Hancock, 2003; Creditor, 1993). These iatrogenic problems potentially made the return home very challenging for the frail older adult. When new physical problems are combined with a marginally adequate care situation at home, serious physical and social problems invariably result. Questions about how decisions are made regarding home discharge and how the discharge planning process can be made more effective have challenged nurses and social workers for decades (Congdon, 1994; Hyde, Robert, & Sinclair, 2000).

Frail older adults, their families, and HCTMs view decisions from dramatically different paradigms.   The challenge is to identify and understand the unspoken values and beliefs of the older adult and their family. Children think they know their parent's wishes, but the reality of what their parents wanted actually want may be quite different from the child's perceived reality. Older adults may also demand to go home when others involved in the discharge destination decision are concerned that they will be unable to adequately and safely care for themselves. If the principle parties are unable or unwilling to have an open discussion about their individual concerns about discharge, realistic choices about care become limited.

Conceptual Framework

The conceptual framework for this study is the Circle of Control Model of Health Care Decision-Making Model (COC of HCDM). Decisions about discharge destination are complex and involve the frail older adult, their family members, and HCTMs. The physical, emotional, and cognitive abilities of the frail older adult affect not only what decision is made, but also how decisions are made. The discharge destination may have consequences for both the frail older adult and their family members. This framework was chosen because it is robust enough to explain the dynamic physical and social forces at work when decisions are made about the discharge destination after hospitalization.

The model was developed from an analysis of the decision-making literature (Popejoy, 2005) and was influenced by Bronfenbrenner’s (1979, 1986) Ecological Model of Human Development. Bronfenbrenner’s (1979) organizing framework explained how nested structures (microsystem, exosystem, and macrosystem) within an individual’s environment (mesosystem) influenced human development. The Circle of Control (COC) explains how internal (microsystems), external (exosystems), and system (macrosystems) influences affect each individual in the COC as people function between different settings (mesosystems) and make decisions about how much control they desire to keep or give away when making a particular decision. The premise behind COC of HCDM is similar to Bronfenbrenner’s model in that decisions made by adults are rarely made by individuals in isolation from others. People who are in the person’s environment influence the individual making the decision.

The COC of HCDM model explains how internal, external, and system influences uniquely affect each individual who is involved in a particular health care decision. For the decision to be seen as an acceptable choice, a level of congruence (O’Connor, 1997; Roberto, 1999) between internal, external, and system influences must be present. Congruence requires that there be contiguous, proximal social units that impinge on one another directly and significantly. These social units must have a unit of exchange; in this model the unit of exchange is health care decision-making. Decisional congruence is agreement between the older adult, their family, and health care team members about the essential elements of health care decisions (Eckstein, 1997). Thus in the COC of HCDM model, if any one of the participants in the decision perceives incongruence, the decision is renegotiated between the participants until an acceptable level of congruence is met and the decision is once again balanced (Figure 1).

Internal, External, and System Influences

Internal influences. Conditions that arise from a fundamental belief structure of an individual that has developed over time as a result of life experiences are characterized in the COC of HCDM model as internal beliefs. Life context is basic to how people view the decisions they make. Life context includes past and present viewpoints, events and relationships, socioeconomic, personal, and cultural characteristics (Facione & Giancarlo, 1998; Kelly-Powell, 1997). Basic to internal viewpoints are personal values and beliefs, which serve as a filter for processing information related to decisions and are integral to the decision-making process and outcomes (Kelly-Powell, 1997; Pierce & Hicks, 2001).

The degree or extent of desired involvement in the decision-making process is also an internal influence. Degner et al. (1997) and Benbassat et al. (1998) identified three roles of involvement in health related decision-making (a) active, (b) collaborative, (c) passive. Benbasset et al. additionally identified a fourth category of avoiding information. Degree of involvement is also influenced by severity of illness, education, ethnic group, gender, age, family role expectations, prior experiences, and type of decision (Clark, Wrey, & Ashton, 2001; Davison, Degner, & Morgan, 1995; Mansall, Poses, Kazis, & Duefield, 2000; Shawler et al., 2001).

In the ill frail elderly adult decision-maker, competence often becomes an issue that must be addressed by the family and HCTMs. To be competent to make a decision, an individual must have rational capacity, sufficient knowledge about his or her situation, and no internal (mental or emotional) or external (physical) constraints (Capitman & Sceigaj, 1995). When older adults cannot or will not speak for themselves lack of congruence among the decision-makers may occur, which in turn may set the stage for decision conflict, which is the lack of agreement between the presented alternatives and the older adult's value system (Pierce & Hicks, 2001). Decisional conflict is more common in major decisions that are highly emotional, have high stakes in terms of gains or losses, require tradeoffs, and have a high likelihood of decisional regret (O'Connor, 1995).

When the frail older adult makes decisions about how to organize care at the time of discharge, physical functioning is as important to consider as cognitive functioning. The degree of frailty, the number and type of functional limitations and the presence of frank disability are influences internal to the older adult. What is internal to one member of the COC may be an external influence to another member. For example, the older adult who cannot bathe themselves or cook for themselves may believe they can continue to live at home, but his or her family member may view the situation quite differently and become concerned that the elder can no longer live at home without some sort of assistance.

External Influences

External influences do not arise from the individual’s fundamental belief structure, but are generated by the circumstances particular to the decision under consideration. For example, when frail older adults have made the choice to go home instead of going elsewhere for continued rehabilitation, and those who provide support or care for them are worried that they are too physically weak or disabled to get dressed, go the bathroom, or cook for themselves, those concerns become part of the external influences that affect members of the COC. The principal stakeholders in discharge destination decisions must address these concerns or there will be little congruence about the decision.

Often health care decisions are very complex, and decisions ultimately affect not only the frail older adult, but also the family, and members of the health care team who assist with planning the discharge and are responsible for follow-up with care needs. How issues are identified and addressed can make the difference between concerns being addressed in a forthright manner and planned for, or ignored and not attended to. The willingness of decision-makers to address issues may be a result of how decisions are framed. Decisional framing refers to the emphasis placed on different aspects of the decision-making situation by the decision-makers (Tversky & Khaneman, 1981). For example, the use of expert opinion can either be used by HCTMs to encourage input into the process by the older adult and their family member, or to stop all communication by quieting the older adult’s and their family members’ voices about their wishes for care and treatment (Opie, 1998; Shawler et al., 2001).

Decisions about safety are particularly prone to conflict and expert power influences because of the strong emotional content associated with those decisions (Opie, 1998).

For decision-making to actually occur about a health care situation there must be a number of options or choices available (Tversky & Khaneman, 1981). One of those choices can be for the older adult to ignore the concerns and recommendations of family members and HCTMs and continue on a course of action they believed best. The difference between a disastrous health care decision-making situation and a challenging, but organized one, is the presence of open communication and available support systems.

System Influences.

System influences are the sources of care and support that are accessible to the older adult as they make health care decisions. By far most of the care received by older adults is informal care from a network of family, friends, or neighbors (Roe, Whatmann, Ryoung, & Dimond, M., 2001). Families are often both the preferred and actual source of support for three-quarters of frail older adults who live in the community, regardless of ethnic origin (Tennstedt, 1999). It is more common for ethnic groups such African-Americans and Latinos to use informal sources of care than Caucasians (Johnson, & Tripp-Reimer, 2001). Caregiving is not often a shared activity among family; one family member, most often the spouse, will give most of the care (Tennstedt, 1999). When the frail older adult does not have a spouse, a daughter or another female relative are often the lone caregiver (Brewer, 2001). Neighbors and/ or friends are not generally the primary care provider, but may give care as a form of supplemental assistance (Tennstedt, 1999).

Informal care that occurs in the home setting may be supplemented by formal care. This form of formal care is either paid for privately with personal funds, long-term care insurance, or through government programs such as Medicaid or Medicaid Waiver

Programs (LeBlanc, Tonner, & Harrington, 2001). Capitman and Sciegaj (1995) identified that older adults who have sufficient financial assets and good health have a greater variety of options available to them than those older adults who are in poor health and have financial limitations. Tennstedt (1999) found that as debility increased, the receipt of informal services increased more rapidly than use of formal services, with family and other informal caregivers filling the care-giving gap. Adults with less social support, such as those who were unmarried, lived alone, or lived in pubic housing were more likely to receive formal services, such as in-home or institutional care (Tennstedt).

Ultimately, when frail older adults who live in the community or in their own homes or apartments can no longer obtain formal or informal help and support, decisions about relocation must occur. These decisions about where older adults will live are complex and involve many different people and occur in a number of different settings, of which the hospital is one such setting (Forbes, Bern-Klug, & Gesert, 2000; Johnson & Tripp-Reimer, 2001). The need to make decisions about living arrangements after discharge from acute care are often difficult and are the result of a significant change in health status, accompanied by the possible deleterious effects of hospitalization and early discharge, and the inability to meet one's own physical care needs (Naylor et al.,1994).

Model Function

External and system influences impact each participant in the COC; thus, the arrows are pointed inside the COC representing the direct relationship of those two influences on participants making health care decisions. Internal influences are distinctive to each individual participant in the COC. Each individual's internal influences impact every other individual in the COC, but can also change the dynamic of internal and external influences. Thus, the arrows for internal influences point to the other participant's circles and extend outside the larger COC. The arrows are intended to demonstrate the fluidity of health care decision-making, and the impact that each individual participant in the COC has on the dynamic relationship between individuals and situational elements that relate to health care decision-making.

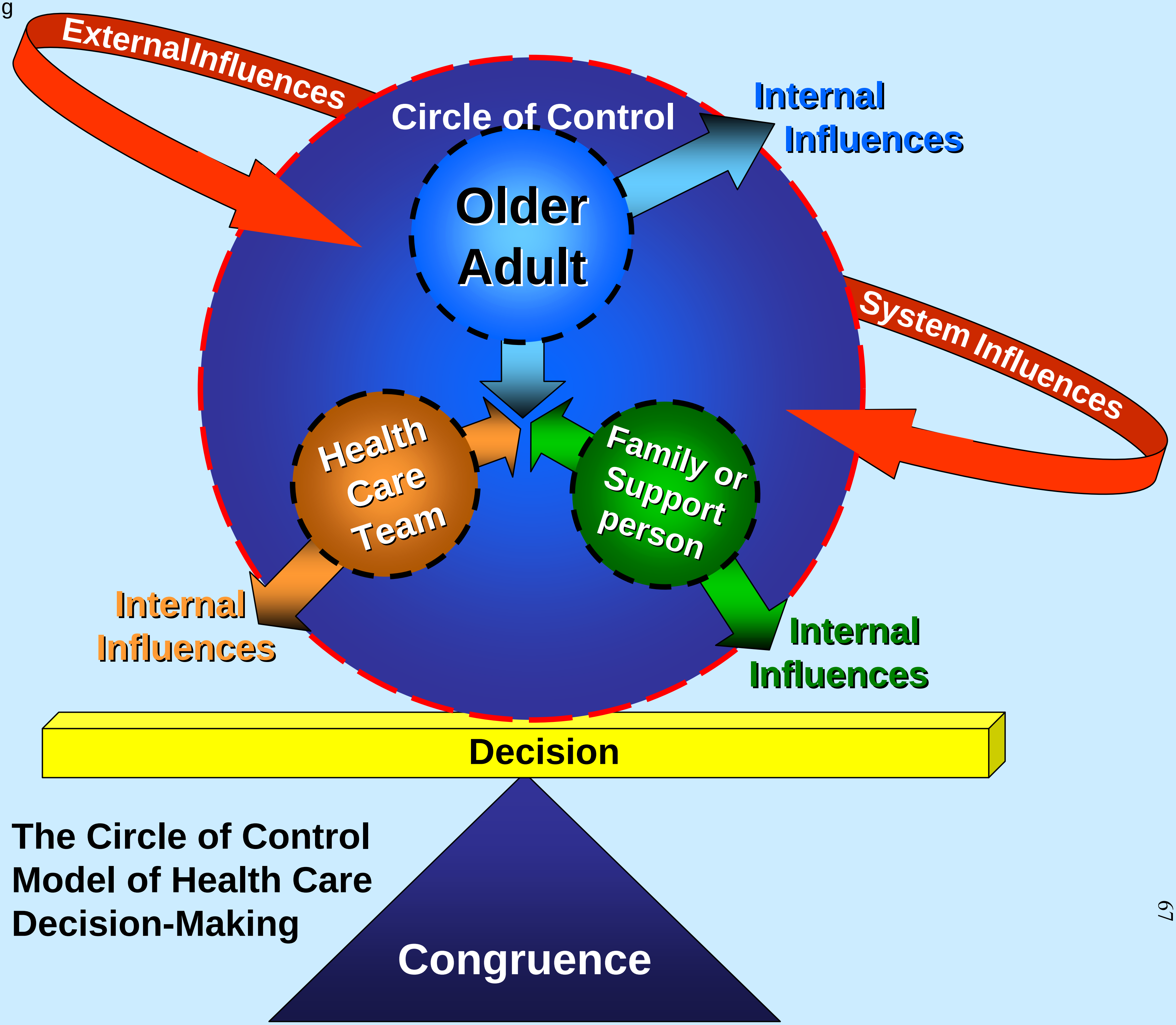
The Decision

The COC remains centered and balanced when all participants in a health care decision achieve congruence and agree about the decision under consideration. The concept of congruence is represented by an equilateral triangle upon which the decision rests (Figure 1). If any one decision-making participant does not achieve congruence with the decision made, then the balance within the circle of control changes and it is no longer possible for the COC to remain centered on the decision. At the point that the decision is no longer balanced, participants will renegotiate the decision to achieve congruence and balance the decision.

Summary

The number of elderly will begin to increase rapidly within the decade. By the year 2010 the numbers of oldest old who are more prone to conditions related to frailty will significantly increase and potentially outstrip the ability of the younger members of society to give care. There is little known about how much participation frail older adults, their family members, and HCTM want to have when making decisions about discharge destination for hospitalized frail older adults. There is substantially less known about how frail older adults, their family members, and HCTMs, who may have very different views of the decision, achieve congruence about the frail older adults discharge destination. It is currently very difficult for HCTM assist hospitalized frail older adults and their family members with these complex and difficult choices about discharge destination. It is equally difficult to develop meaningful nursing interventions to help older adults, their families, and members of the health care team to make decisions about discharge destination when little is understood about how congruence is achieved between the three groups. The proposed study aimed to help to close the knowledge gap that exists about how decisions are made and congruence is achieved by those who are involved in making discharge destination decisions with the hospitalized frail older adult.

Figure 1, Circle of Control Model of Health Care Decision-Making



CHAPTER 3

Methods

Design

A descriptive design occurring over a 21-month period employing mixed methods that combined semi-structured qualitative interviews with quantitative questionnaires described how hospitalized frail older adults, their family, and health care team members (HCTM) made discharge destination decisions (Table 3). This design enabled the investigator to address three specific aims: (1) the preferred level of participation (LOP) in the discharge destination decision of (a) the frail older hospitalized adult, (b) the same older adult's family member, and (c) the HCTM most involved in the decision; (2) the extent that congruence between preferred LOP and actual LOP about the discharge destination decision occurred for the same individuals; and (3) the participants' perceptions of the discharge destination decision.

Sample

Sample Size

The sample consisted of 13 frail older adults, 12 key family members, and 7 HCTMs. Within this sample if frail older adults 8 females and 5 males were recruited, consistent with the demographic profile of older adults. The statistician consulted did not recommend a power analysis to determine sample size, because this was an exploratory study and little was known about how triads of people worked to make decisions about hospital discharge. Thus, the statistician recommended that the sample size be based upon the goals of the study. A sample size of 12-20 participants was chosen because it was sufficient to identify disconfirming evidence and show maximum variation in the data

(Kuzel, 1999). Data collection ended once redundancy, defined as duplication of similar ideas, meanings, and experiences was achieved and no new information was forthcoming (Morse, 1994, p. 106).

Inclusion criteria. Inclusion criteria were: (a) age 70 years or older, (b) admitted to the hospital for a stay that was 24 hours or longer, (c) a primary medical diagnosis without surgical intervention, (d) score of ≥ 3 on short form Mini Mental State Exam (SMMSE), and (d) score of ≥ 2 on the Frailty Phenotype.

Exclusion criteria. Exclusion criteria were: (a) known diagnosis of dementia, (b) score of < 3 on the SMMSE, (c) score < 2 on the frailty phenotype measure, (d) inability to participate in an interview due to fatigue, illness, or profound sensory problems that precluded conversation (e) no family or fictive kin to interview, or (f) currently living in a nursing home, residential care, or assisted living facility.

Setting

The chosen hospital had 375 acute care hospital beds, was a voluntary, not-for-profit, full service tertiary care center, and was located in a moderate size community in the Midwest where a major University was located. The hospital had a nursing unit that primarily served patients with general medical diagnoses. The medical unit used a nurse outcome coordination model to identify patients' discharge needs in a timely manner. Outcome coordinators worked with patients, staff nurses, and assigned social workers to identify discharge needs such as patient and family knowledge of disease and treatment, patient support at home, and requirements for formal service use.

The American Hospital Directory Website reported that in 2005 the hospital had 1,638 Medicare patients admitted to the medical unit for an average length of stay (LOS) of 5.76 days. There were no public data available to identify the number of patients discharged from this hospital to skilled or nursing home care, but it is generally accepted nationally that approximately 20% of older adults are discharged from a hospital to a nursing home (Berstein et al., 2003). The study site was able to confirm that they had 1,014 patients admitted to their unit over a 9-month period who were eligible for Medicare; of that number, 209 were discharged to a skilled nursing facility and 23 to an intermediate level of care. There were no publicly reported data for BHC specifying the types of diagnoses for which these patients were admitted.

Recruitment

After obtaining Health Services Institutional Review Board (IRB) and Community Hospital IRB approval for the study, the investigator presented an inservice to the nursing and social work staff of the hospital unit about the study purpose, inclusion, exclusion criteria, and recruitment procedures. Until recruitment ended the investigator talked with the nurse outcome coordinators of the medical unit 5-7 days a week to determine if there were any older adults meeting the inclusion criteria. If there were potential participants, then the nurse, social worker, or outcome coordinator sought permission from the patients for the investigator to visit them to describe the study purpose and procedures. Subsequently, the investigator visited the patients to ascertain their willingness to participate.

Older adult. If the frail older adult was interested in participating in the study, informed consent was obtained, a study identification number assigned, and SMMSE was administered. Those participants scoring <3 on the SMMSE were thanked for their time and received no further contact. If the participants scored ≥ 3 the test for frailty was administered. No further data collection ensued if the participants were not preclinically frail (2 indicators) or frail (≥ 3). They were thanked for their time and no further contact was made.

If the participants met the SMMSE and frailty phenotype cutoff scores, the older adults were asked if they felt well enough to continue to data collection. The investigator asked the older adult which family member they believed was most influential in helping them make a decision about discharge destination. The investigator sought permission from the older adults to contact their family member. If the identified family was not present at the hospital, the older adults were asked when they expected the family member to be in the hospital or were asked for contact information. If they could not provide the information the investigator asked the older adults for permission to obtain the information from nursing staff. If the older adults did not have family or fictive kin helping them with decisions they were thanked for their time and no further study contact occurred.

The older adults also were asked which nurse, outcome coordinator, or social worker was participating with them in making discharge destination decisions. Early in the study it became apparent that older adults did not know the name of the HCTM working with them. This was an anticipated problem, therefore the HCTM who was the nurse, social worker or outcome coordinator assigned to that participant was asked to participate in the study.

Prior to conducting the older adult's data collection the investigator determined that both the family members and HCTMs were willing to participate in the study. If either the family member or HCTM was not willing to participate, or no other person who was equally able to fulfill the role could be identified, no further data collection occurred. The investigator met with the older adults to explain that no further data collection would occur and thanked them for their time. There were six older adults who did not have family willing or available to participate. All HCTMs agreed to participate.

Family members. The investigator told the participant-identified family member that they were identified as the person who was helping make the discharge destination decision. They were asked if they were willing to participate, if so, consent for the study was obtained. If they declined participation, no further contact was made. As identified previously, the investigator returned to the patients and asked them if there was another family member who was also working with them that the investigator could contact. The same procedure for obtaining consent applied. If there were no family members willing to participate, the investigator returned to the older adults, explained that their family members were unable to participate, thanked them for their time, and made no further contact. All family members who were approached agreed to participate in the study

HCTM. There were four outcome coordinators and two social workers that routinely worked with patients on the medical nursing unit. The investigator met with each of these individuals after IRB approval had been obtained and just prior to the beginning of data collection, to explain the study procedures and to ask if they were willing to participate if identified by a patient. The staff members that were selected to participate completed consent procedures at the time of the first interview. All HCTMs were nurses, outcomes coordinators, or social workers. No HCTM declined participation in the study. It was anticipated there would be times when the same staff member would be involved with discharge destinations for multiple patients. The staff members were told about that possibility and were informed that they would subsequently be contacted a second time if a patient identified them as the staff person most involved in their discharge decisions. Four out of seven HCTMs were interviewed multiple times.

Instruments

Short Mini Mental State Exam (SMMSE)

This six-item cognitive screening instrument included a three-item recall of objects (apple, table, and penny) and three-item temporal orientation section (day of week, month, and year) with a range of scores from 0-6, where higher scores meant better cognition (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002). The instrument was designed as a screen for cognitive impairment in studies testing interventions and/or using self-reports (Appendix 1).

Callahan et al. (2002) tested the SMMSE in an Alzheimer's Disease Center (ADC). The sample included cognitively impaired older adults with a mean age 69.2 years (range 21-92), who were primarily women (57.1%), and Caucasian (93.1%), with 12.5 average years of education. When the cutoff score was set at ≥ 3, the six-item screen had a sensitivity of 74.2, specificity of 96.0, positive predictive value (PPV) of 96.7, and a negative predictive value (NPV) of 70.1 (Callahan et al.). The instrument was also tested in a community-based sample of older African American (AA) adults. The sample included primarily women (59.4%) with a mean age of 74.4 (range 65-99), an average of 10.4 years of education, and a diagnosis of cognitive impairment. When the cut-off score was set at ≥ 3, the six-item screen had a sensitivity of 50.4, a specificity of 97.4, a PPV of 87.2, and a NPV of 84.5 (Callahan et al.). Higher sensitivity levels optimize negative predictive value (meaning that the screening instrument correctly identifies that a condition doesn't exist).

Results from the MMSE long form tested in both populations using a cutoff score of ≤ 24 as suggested by Folstein and Folstein (1994, p. 224), had a sensitivity of 77.2, specificity of 94.4, PPV 95.7, and a NPV 72.3. The results in an African American (AA) population were similar, with a sensitivity score of 53.3, specificity of 92.1, PPV of 70.9, and a NPV of 84.6. At this cutoff point, the long and short form MMSE performed similarly, therefore a score of ≥3 was chosen for the SMMSE. The SMMSE performed well in elderly Caucasian and AA women who had completed 10 to 12 years of education. This measure was used in a similar population in this study. The SMMSE is shorter and less burdensome to participants than the long form, taking only 3-5 minutes to administer, and can easily be incorporated into the first few minutes of an interview without creating any emotional discomfort or exhaustion for the frail older adult.

Frailty Phenotype

The frailty phenotype identifies the presence of clinical or preclinical frailty in community-dwelling older adults (Fried et al., 2001). It consists of a combination of elements that include questions about unintended weight loss, exhaustion, and amount of physical activity. There are two direct measures: walking time and grip strength. Weight loss is assessed by the question, "in the past year have you lost more than 10 pounds unintentionally?" If yes, then the participant was scored as positive for the weight loss criterion for frailty.

Exhaustion was measured using two questions from the CES-D Depression scale. The two questions were: (a) I felt that everything I did was an effort; (b) I could not get going. These questions were scaled on the question of "how often in the past week did you feel this way?" Scores ranged from 0 (rarely or none of the time), 1 (some or little of the time), 2 (a moderate amount of the time), and 3 (most of the time). Scores of 2 or 3 were scored as positive for the exhaustion criterion for frailty.

Physical activity assessment was based on questions from the Minnesota Leisure Time Questionnaire about walking, doing chores, mowing the lawn, raking, gardening, hiking, jogging, biking, exercise cycling, dancing, doing aerobics, bowling, calisthenics, swimming, playing golf, singles or doubles tennis, and racquetball. These data were used to identify kilocalories (Kcal) expended per week using the formula Kcal = Metabolic Equivalent Level (MET) x hours of activity x kilogram (kg) body weight. These results were stratified by gender. Men expending < 383 kcal and women expending < 270 kcal were considered positive for the physical activity criterion for frailty. Walking time was stratified by gender and height; grip strength was stratified by gender and BMI. Those who had 1 to 2 criteria present were preclinically frail; those with ≥ 3 criteria present over all of these parameters were considered frail. The frailty phenotype took approximately 15 minutes to administer by the PI (Appendix 2).

Historically, physical frailty has been difficult to quantify and was often measured by proxy measures such as capability in activities of daily living (ADL) and instrumental activities of daily living (IADL). The frailty phenotype offered an improvement over these proxy measures as it directly measured the physical syndromes known to contribute to frailty. However, what it failed to do was measure the social elements inherent in frailty.

Using the Cox proportional hazards model, the frailty phenotype (those with ≥ 3 criteria present) was found to be independently predictive of major geriatric outcomes estimated over 3 years (Fried et al., 2001). The unadjusted ratios were: (a) mortality (hazard ratio unadjusted) (HR 2.42; CI 1.84, 3.19; $p < .0001$), (b) hospitalization (HR 1.38; CI 1.26, 1.51; $p < .0001$), (c) first fall (HR 1.36; CI 1.18, 1.56; $p < .0001$), (d) worsening ADL ability (HR 2.54; CI 2.16, 3.00, $p < .0001$), and (e) worsening mobility (HR 1.94; CI 1.75, 2.15, $p < .0001$). The unadjusted hazard ratios for intermediate frailty (1 to 2 frailty indicators present) were: (a) mortality (hazard ratio unadjusted) (HR 6.47; CI 4.63, 9.03; $p < .0001$), (b) hospitalization (HR 2.25; CI 1.94, 2.62; $p < .0001$), (c) first fall (HR 2.06; CI 1.64, 2.59; $p < .0001$), (d) worsening ADL ability (HR 5.61; CI 4.50, 7.00, $p < .0001$), and (e) worsening mobility (HR 2.68; CI 2.26, 3.18, $p < .0001$) (Fried et al.).

When adjusted for the covariates of age, gender, minority cohort, income, smoking status, brachial and tibial blood pressure, fasting glucose, albumin, creatinine, carotid stenosis, history of CHF, cognitive function, major electrocardiogram abnormality, use of diuretics, problems with IADLs, self reported health measures, CES-D modified depression measures, the frailty phenotype (those with ≥ 3 criteria present) were predictive of mortality ($p < .0001$), hospitalization ($p < .014$); first fall ($p < .056$), worsening ADL ability ($p < .0001$) and worsening mobility ($p < .0001$). Intermediate frailty (1-2 indicators of frailty) was similarly predictive of mortality ($p < .0001$), hospitalization ($p < .004$), first fall ($p < .054$), worsening ADL ability ($p < .0001$), and worsening mobility ($p < .0001$) (Fried et al.).

Demographic Questionnaire (DQ)

The investigator-developed DQ addressed age, gender, race, marital status, number of living children, years of education, living situation, reason for hospital admission, illnesses in addition to the one for which participants were hospitalized, ADLs, and IADLs. The DQ for family members paralleled the questionnaire for the older adults, except the family members were asked to identify any assistance the older adult received. The DQ for the HCTM had a different focus, as the investigator was not interested in their personal living situation. The questionnaire included questions about age, gender, race, type of nursing or social work degree held, any advanced degree, specific position held, number of years worked, and type and number of positions held in the previous 5 years. The investigator administered the questionnaires at the time of enrollment. The DQ took approximately 5-10 minutes to complete (Appendix 3, 4, 5).

Control Preferences Scale (CPS)

The CPS was developed to measure how people with life-threatening illness made decisions, and consists of five cards (A,B,C,D,E) each portraying a different preference for level of involvement in decision-making and a cartoon illustrating different decision-making preferences. The five cards represent three general categories of preference for involvement in decision-making, statements A and B characterized active decision-making, statement C represented collaborative decision-making, and statements D and E represented passive decision-making (Degner, Sloan, & Venkatesh, 1997) (Appendix 6, 7, 8).

The control preference statements may be altered slightly to reflect the decision-making situation under study (Degner et al., 1997, p. 37). Degner et al. contended that the item wording of the CPS is general enough to apply to a wide variety of health-related conditions. For this study, the wording of the cards reflected decisions about patient's discharge destination. The role that the patient, family member, and HCTM assumed was slightly different, so each group (patient, family member, HCTM) participated in a card sort that was developed to represent their LOP in making the discharge destination decision (Table 1).

There were several approaches that could have been used in card selection or sort (Degner et al., 1997). For this investigation a 5-card sort was used. This method was chosen because the investigator had good control over the testing procedure, had adequate time to explain the procedure, had a place to present the cards, and wished to minimize error by using every subset of two cards. Order of card presentation impacts reliability of the data and only fixed order presentation or every subset of two was shown to be reliable in past studies (Degner et al.). The 5-card fixed order method required that participants make a total of 10-paired comparisons by sorting a series of five cards (ABCDE). The cards were presented in a fixed manner two at a time (AB, BC, CD, DE, AC, BD, CE, AD, BE, and AE) to the older adult, family member, HCTM (Figure 2, 3). Presentation of the cards in this way resulted in participants comparing all possible combinations of the five cards. Each card A, B, C, D, E, had a description of the decision under consideration and a cartoon that visually described it. On the back of each card the letter was identified, so that the participant did not see the letter. The participants were shown each card pair, starting with pair AB, and were asked which one of these best described their preferred LOP in decisions. The investigator wrote each selection down.

Each subsequent card pairing was handled the same way until selections were made about all 10 pairs.

Once the total preference order was obtained, participants were asked to select the one card that was closest to the role they actually assumed in making the discharge destination decision (Degner et al., 1997). An additional card was added to the card sort to address the situation in which patients and health care providers desired only to work with the patient's family. After the CPS procedure was completed, the PI asked the patient and the HCTM if the 6th card represented their viewpoint about level of family involvement, yes or no. This allowed the investigator to discern more specifically the role of family members, separate from the role of the HCTM in the discharge destination decision.

Using the card-sort technique assured that participants selected their rank ordering of preferences only after each possible combination of two cards was considered. Measurement error was minimized with this approach (Degner et al., 1997). The premise of this method was that people have systematic preferences about the degree of participation they desire when making health care decisions. There were many possible pairings of cards but only 11 pairings were considered valid for the CPS measure.

Semi-structured interview guides

Questions for the semi-structured interview guide were very brief (Appendices 9, 10, 11). They were designed to elicit information about perceived decisional congruence between the frail older adults, their selected family members, and HCTM. As identified in the Circle of Control-Health Care Decision Making (COC-HCDM), health care decisions are quite varied and include issues related to internal, external, and system influences. Therefore, a few brief questions were developed that addressed congruence with the decision, other choices considered, and people involved in the discharge destination decision.

Each participant was interviewed separately so they were not aware of what others had said. Interview guides were developed following recommendations by Johnson (2001). First, Johnson recommended questions that were developed specifically to "break the ice." The interview was the last item after the DQ and the CPS scale were administered, so it was not unnecessary to have questions specifically designed to break the ice. The same process was used for older adults, their chosen family members, and HCTM.

The interview for frail older adults included questions designed to elucidate the range of options they may have considered when making the choice about their discharge destination. The questions were designed to encourage the participants to talk about the full range of options they believed they had available to them when making the choice about discharge destination, the issues that needed to be planned for prior to discharge, and their overall satisfaction with the degree of participation of members of the triad. The interview concluded with a general question about other information that the participants would like to communicate, and a general summation of the points made during the interview in order to explore any points that needed any detail or clarification further detail (Johnson, 2001).

Interviews were planned to unfold in a particular way, however digressions did occur. The investigator embraced these digressions from the plan, as they were productive and offered a broader understanding of the phenomena under study.

However, the investigator also had to return the interview to the intended path so that the list of questions asked was consistent between participants. When the participants had completed stating their thoughts about the topic at hand, the investigator asked the next intended question from the interview guide. Immediately after the interviews were completed, the investigator dictated field notes about significant features of the interview, including social interactions that added detail and context to the transcribed data.

Procedures

The investigator, using a DQ, obtained descriptive data about older adult participants, their chosen family members, and a HCTM. Information about preference for decisional control was obtained from the older adults, their chosen family members, and a HCTM by completing the Control Preferences Scale. Accounts of perceived congruence or incongruence in the decision were gathered using a semi-structured, audiotape-recorded interview with the same triads

Data Collection

Data collection, including family member and HCTM interviews, occurred while the participants were still hospitalized and within 24-48 hours of planned discharge to home. The investigator collected all data in an interview format, using measures described in the next section. HCTM caring for the patient were asked to estimate the time frame for discharge, because many hospitalized patients are not knowledgeable of their anticipated date of hospital discharge. However, discharge dates were estimates and were not accurate in all cases. The actual time from data collection to expected discharge varied. The possibility that data collection would be completed and patients would remain hospitalized for longer than 48 hours was anticipated. This possibility did not negatively impact meeting aims of the study or the relevance of the data. The interview questions addressed the discharge destination decision, as participants knew it at that time.

After determining that both the family member and the HCTM were willing to participate in the study, the demographic questionnaire (DQ) was the next instrument administered to the older adult. The DQ was a short instrument and took no longer than 5 to 10 minutes to complete. At the end of this data collection, the participants were asked about their level of fatigue. If participants were too tired to continue, a second visit was planned the next day to complete the Control Preferences Scale (CPS) card sort and semi-structured interview. It was anticipated that together these activities would take approximately 30-40 minutes to complete. However, the length of time varied depending on how much participants wished to contribute to the interview (Appendix 12)

If the family member was willing to participate, and after consent was obtained, the DQ, CPS card sort, and a short semi-structured interview took place in a private location in the hospital away from the patient's room (Appendix 13). There were three occasions when the family member did not want to leave the room while the patient was interviewed, nor did they want to leave the room for the interview. In those instances the older adult and family were interviewed together. The study procedures for the older adult were done first, followed by the family member. The DQ took 5-10 minutes to complete, the card sort and interview took from 30 to 45 minutes to complete depending on how much the family member wished to contribute.

If the HCTM was willing to participate, it was verified that consent had previously been obtained and if not, consent was obtained (Appendix 14). The DQ, CPS card sort completion and a short semi-structured interview took place in a private location in the hospital away from the patient's room. The DQ took 5-10 minutes to complete, the card sort and interview took from 30 to 45 minutes to complete. The time varied depending on how much the HCTM wished to contribute. The HCTM was interviewed at a time that was convenient for them and did not interfere with their work duties.

In instances that the HCTM was involved in more than one discharge, the DQ was administered one time, at the first interview. There is little known about the stability of the CPS scale over time for the same participant (Hack et al., 2005). There have been no studies that longitudinally address stability of the instrument when used with HCTMs in a relatively short time frame. Thus, a conservative approach to this issue was taken. If the same HCTM was included in the study for more than one patient, the CPS and the interview were administered each time relevant to the patient's situation.

After data collection was ended no further contact with that patient or their family was made. A change in the patient's condition between the end of data collection and actual discharge had no influence on data that were already collected, as no longitudinal data were collected. Conversely, if data collection was underway and a significant change in the patient's condition occurred, data collection for that patient was stopped. A significant change was an unanticipated medical emergency that resulted in a change of intensity of care either to a step-down or intensive care unit for greater than 24 hours. This type of change in condition generally required a major revision in discharge plans, making data that was still being collected and not completed not applicable to their current situation.

If the older adult was discharged before all data were collected, the participant was dropped from the study. Decisions about discharge were likely to be viewed much differently before patients leave the hospital than after discharge. To avoid the possibility that people already discharged viewed the discharge destination decision differently than those who were still hospitalized, frail older adults who were discharged prior to completing the interview were dropped from the study.

If, when the investigator returned the next day, participants were no longer in their previously assigned hospital room, information about their new location and condition was sought from a HCTM familiar with the patient. As described above, if participants had a significant change in their condition no further data collection occurred.

Participant burden. Because the older adult participants were ill, the investigator limited the time spent in each data collection sessions so that participants did not become too fatigued. The total time required to complete their data collection varied but did not take more than one to one and one-half hours. Careful consideration was given to the fatigue level of the participant who was beginning the recovery phase of acute illness. Family members also risked becoming fatigued or stressed. Therefore, the interview was planned at a time that was convenient for them. If the family members became fatigued, data collection was stopped, and another meeting arranged. HCTMs were very busy. Therefore, the measures used for data collection from HCTMs were designed to be efficient and took approximately 30-45 minutes. Interviews were arranged for HCTMs at the hospital in a private location at a time that was convenient for them. If they needed to stop the interview prior to finishing, the interview was rescheduled for later that day or immediately the next day.

Data Analysis

Aim #1

Aim #1**:** To identify the preferred LOP in the discharge destination decision of (a) the frail older hospitalized adult, (b) the same older adult's family member, and (c) the HCTM most involved in the decision.

Data derived from the SMMSE, DQ, and Frailty Phenotype was analyzed via descriptive statistics to describe the demographic characteristics of older adults. Frequencies and percentages were used to analyze the categorical variables of gender, race, living arrangement, marital status, and reason for admission. Means, medians, standard deviations and ranges were used to describe numeric variables such as age, years of education, SMMSE, and Frailty Phenotype scores. For both the chosen family member and HCTM data derived from the DQ was analyzed via descriptive statistics as described above for the older adult.

The reliability criterion identified by Coombs (1964) was that for the 5-card sort (ABCDE), 50% plus 1% of preference orders must fall on the CPS 1-11 metric (Table 2). Valid preferences were identified by the order of the cards and their associated midpoints and indicated that the specific health care decision fell on a systematic metric of responses (Coombs; Degner et al., 1997). For instance, those who wished to have the most extreme levels of participation, representing the most active end of the metric, would arrange the cards in the order (ABCDE) and received an ordinal score of 1. The next most extreme score would be (BACDE) and received an ordinal score of 2 indicating a lesser preference for control. The scoring continued this way to score

11(EDCBA), which was the least amount of participation and represented the passive end of the metric and is also the reverse permutation of score 1 (ABCDE).

Coombs (1964) suggested that data that did not fall on the metric be discarded. Degner et al. (1997) identified several approaches to successfully retain data for analysis. One approach was to rank the preference numbers from 1-120 and proceed with ordinal level data analysis. The second approach was to review the metric looking for systematic error, e.g. the same invalid data occurs over and over again suggesting for that population the card was valid. It was also possible that areas that were “just noticeably different” would occur. This issue would cause confusion for the participants as they attempted to make clear choices between the cards. With this type of data problem, Degner et al. (pg. 33) suggested the metric be collapsed in those areas that are “just noticeably different” and redistributed.

There were also suggestions for converting data to categorical variables based on the participants’ most preferred level of involvement Active (A, B), Collaborative (C), or Passive (D, E). Another approach was to categorize data based on the two of the preferred levels of involvement, Active-Active (AB, BA), Active-Collaborative (CB), Collaborative-Passive (CD), Passive-Collaborative (DC), and Passive-Passive (DE, ED).

For this study, data that did not fall on the metric were retained by converting all scores to the two most preferred levels of involvement. For example a participate who selected card A, four times, card B, three times, card C, two times, card D, one time, and card E, 0 times had a card order of A,B, C, D, E. The two most preferred LOP were the first two cards, A and B, which are both active roles. Thus, they would be assigned the two categories of active-active (AB).

Aim #2

Aim #2: To identify the extent that congruence between preferred LOP and actual LOP about the discharge destination decision occurred for the same individuals as described in Aim #1.

Level of congruence was measured by looking for discrepancies between participants' preferred and actual roles. After the card sort procedure was done, all five cards were displayed at one time to the participant. They were asked to choose the card that best described the LOP they actually had in the discharge destination decision. To obtain the measure of discrepancy the first choice from the card sort score was subtracted from the card denoting LOPs in the discharge destination decision. This resulted in a score from 0 (no discrepancy) to 4 (4 steps of discrepancy). A score of 0 means there was no discrepancy between what the preferred LOP and LOP of participation actually assumed by the participant. Scores further from 0 indicate that there was more discrepancy.

An additional card was added to the older adult, family, and HCTMs pick one card sort in order to anticipate the possibility that either the older adult, family, or HCTM would select 'family only' as their preferred LOP in the discharge destination decision. The responses were scored as yes or no.

Aim #3

Aim #3: To describe the participants' perceptions of the discharge destination decision.

The qualitative data obtained from the semi-structured interviews of older adults, their chosen family member, and the HCTM were analyzed from audiotape recordings.

Data about the older adult was being collected from multiple sources in the form of quantitative data and semi-structured interview questions. Qualitative and quantitative data were triangulated in order to strengthen the validity of the qualitative findings (Brink & Wood, 2001, p. 222).

Quantitative data obtained from SMMSE, DQ, Frailty Phenotype, and CPS was used to add detail and context to the qualitative data. These data gave information about the older adult's cognitive abilities, physical functioning, and help received at home with tasks of daily living. There was far less quantitative data available from family members and HCTMs. However, both the DQ and CPS offered some insight into basic demographic details and LOP preferences for these participants. As participants answered interview questions, the investigator used known information from other sources to clarify areas that were unclear or inconsistent.

Qualitative data analysis. The investigator examined transcripts to explicate participants' perceived congruence or lack of congruence about the discharge destination decision. Major themes for decision-making were identified first. According to DeSantis and Ugarriza (2000) there are five aspects of a theme. Themes have patterns and configurations that serve to unify the data, represented the underlying factors, communicate the web or essence of an experience, are woven throughout the data, and exist apart from their individual properties. Each transcript was read looking for data that met the critical elements of a theme. As themes were identified, descriptions that defined the major attributes of each theme were written. Following this clusters of subthemes and micropatterns were identified within and across participant groups. Descriptions of the major attributes that defined each subtheme and micropattern were written. The investigator returned to the data to continue to clarify emerging themes, subthemes, and micropatterns until redundancy in the data was achieved, which meant that no new data emerged from the interviews. The investigator routinely met with her advisor to review transcripts and discuss emerging data themes.

Data trustworthiness. The purpose of the qualitative interview was to derive interpretation; to understand the meanings that participants ascribed to their experiences (Warren, 2001). The epistemology of the qualitative interview is constructivist, not positivist. Thus, the traditional measures of internal and external validity were not relevant; measures of data trustworthiness were used. Kincheloe and McLaren (1998, p. 288) identified two criteria of data trustworthiness: (a) credibility, and (b) anticipatory accommodation. Credibility refers to the portrayal of the constructed reality. The data constructions must be plausible for the data to be considered credible. Leininger (1994) described credibility another way, as the truth, value, or believability of the research findings. The investigator, through observations, engagements, or participation, established with participants that the data were true, valuable, believable, and thus credible. Any comment that did not seem credible was carefully explored with the participant and notations made in the field notes.

The second criterion, anticipatory accommodation, was more complex--investigators gain knowledge from a number of comparable contexts and began to learn from the comparisons of the different contexts. What was known was reshaped to accommodate the unique aspects of what was perceived in the new context (Kincheloe & McLaren, 1998). Consequently, each interview was seen as a unique social encounter between the interviewer and participant, therefore each interview was as distinctive as the individual and their social situation (Warren, 2001). The data were ultimately woven together in such a way that meaningful comparisons were made between the similarities and differences in the experiences so that a plausible and understandable view of the experience was derived.

The criteria of credibility and anticipatory accommodation identified by Kincheloe and McLaren (1998) were determined to be sufficient to establish data trustworthiness for this study. The investigator had an adequate opportunity to talk with and clarify any questions or concerns about the interview responses. Furthermore, the investigator was able to triangulate data findings in order to clarify areas that were unclear or inconsistent. There was also the opportunity to revise interview questions if there was a problem with participant interpretation of a question. In order to make reasonable assurances that the investigator's findings were credible and that anticipatory accommodation had occurred, the investigator routinely met with her advisor to review and discuss data transcripts and coding.

Human Participants Protection

Inclusion of Women

The investigator did not anticipate that recruiting women would be a problem because women age 65 and older represent approximately 58% of the population and 70% of those 85 and older. Men are the minority gender in older adult research; they were recruited as they were available.

Inclusion of Children

No children participated in this study. Participants must have been 70 years of age or older. While discharge decisions certainly impacted children, the nature of those decisions was different. Frail older adults form a specific subgroup of people with unique problems of importance. Therefore this study focused on them.

Inclusion of Minorities

The hospital study site was a tertiary care center and drew patients from across the state. It was anticipated that minority recruitment would follow overall demographic trends, with approximately 8% of the sample (1 participant) being African American and no participants of Hispanic or Asian origin. Attempts were made to recruit minority participants as they appeared in the study hospital.

Sources of Materials

Participants had data collected within 24-48 hours prior to discharge from the hospital. No medical records were reviewed. Participants were not asked for income, social security, or insurance information.

Data management

Study materials were kept in a locked cabinet and arranged as separate files for each participant. Participant identification numbers and data collection dates identified quantitative data, transcribed interviews, and interview audiotapes. Prior to conducting and audio recording an interview, the investigator verbally recorded the participant identification number and the date on the tape. The participants' names were not mentioned. A list of the participant names and assigned identification numbers were kept in a locked drawer separate from quantitative and qualitative data. Consent forms were stored separately from participant lists and data. All quantitative data were double entered into a Microsoft Excel software spreadsheet by the investigator. The investigator did all data cleaning for reconciliation of double entered results.

All interview tapes were transcribed within 7 days of the interview into Microsoft Word and imported directly into Nonnumerical Unstructured Data Indexing Searching and Theorizing (NUD*ST). NUD*ST is software used for qualitative data analysis. NUD*ST uses three basic tools: the Coders, Text Search, and Node Search, which operate on two complementary sets of data. These two data sets are the document system that holds data, research notes, and memos. The node system represents all topics and categories identified by the investigator. These two systems allow for comprehensive management of the project (N6 Reference Guide, March 2002).

Data from frail older adults, family members, and health care team members were analyzed as separate data sets, starting with the frail older adult, then family members, and lastly HCTMs. The investigator transcribed the audiotapes, which allowed for a first general review of the data. The transcripts were then read and themes and subthemes were identified and coded in nodes. As transcripts were analyzed and coded, new nodes were developed. Each node was defined, and a memo was written each time data was added, that described why the coded data belonged in that node, and notes about the meaning of the coded data in relation to other data in the node. This process was repeated until all transcripts were coded.

The transcripts, a tree node map, copies of each node with coded data, and memo pages were then given to the investigator's advisor, who also reviewed the data and discussed it with the investigator. New themes or subthemes identified during this process were added to the nodes, and all transcripts were coded a second time, looking for data that belonged to the new nodes. After this process was completed, the investigator and her advisor once again reviewed the nodes, and discussed emerging themes, subthemes, and analysis. After this was done the investigator combined related themes and subthemes resulting in the final analysis which will be described in Chapter 4, Findings.

Computerized files were password protected and routinely backed up every 24 hours on a second hard drive. Paper backup files were kept in a locked cabinet with participants' paper data files. Audiotape recordings of qualitative interviews were transcribed by the investigator using a dictaphone.

The investigator had completed education (10/6/2004) in protection of human research participants as required by the National Institutes of Health (NIH NOT-OD-00-039). The web-based training was provided by the University of Missouri-Columbia Health Sciences Center and the title of the training session was: "Conducting Human Research." The training included ethical considerations in the Belmont Report, federal regulations, institutional assurances, the IRB review process, ethical recruitment of participants, investigator responsibilities, the informed consent process, and successful completion (with at least 80% accuracy) of an exam on the covered topics. Education about Health Insurance Portability and Accountability Act was also initially completed (3/20/2003) and was updated annually. The web-based training was provided by the University of Missouri-Columbia Health Sciences Center and was entitled "Health Sciences HIPAA Training Quiz", which had to be completed with 80% accuracy. Copies of the training certificates are kept on file by the investigator.

Potential Risks

Potential risks included the risk of injury during the administration of the walking portion of the Frailty Phenotype measure. Prior to helping any older adult get up from a bed or chair, permission was sought from the patient to ask their nurse about their standing and walking ability. Those who were unable to ambulate safely were not tested for walking and were assigned a score of one for that portion of the frailty phenotype. The investigator is a skilled and experienced Gerontological Clinical Nurse Specialist with acute care, home health care, and long-term care experience. The safety of the participant was always of primary concern. The investigator was a member of the nursing leadership staff at the participating hospital. If a fall had occurred, the investigator would have informed hospital staff. After having obtained the patient's permission, a physical assessment would have been conducted by the patient's nurse with the investigator present. The nurse would have been instructed by the investigator to follow their hospital policy for reporting the incident and the investigator would inform the involved IRBs. Any accident that occurred during data collection would have been reported to the involved IRBs within 24 hours. There were no such accidents.

A second risk involved burdening ill, frail, older adults with data collection, therefore careful thought was given to this issue. Instruments that both (a) met the goals of the study and (b) were relatively short and easy to complete were selected. If at any time participants asked to stop, or the investigator in her professional opinion believed it would be unwise to continue, the data collection was stopped and rescheduled for another time. If participants did not want to continue in the study, or the investigator believed they were too weak to participate, they would have been dropped from the study.

A third risk involved the effect of talking about decisions that were part of a potentially difficult discharge process. It was possible that discharge plans could have changed at the last minute to accommodate a different way of seeing the situation.

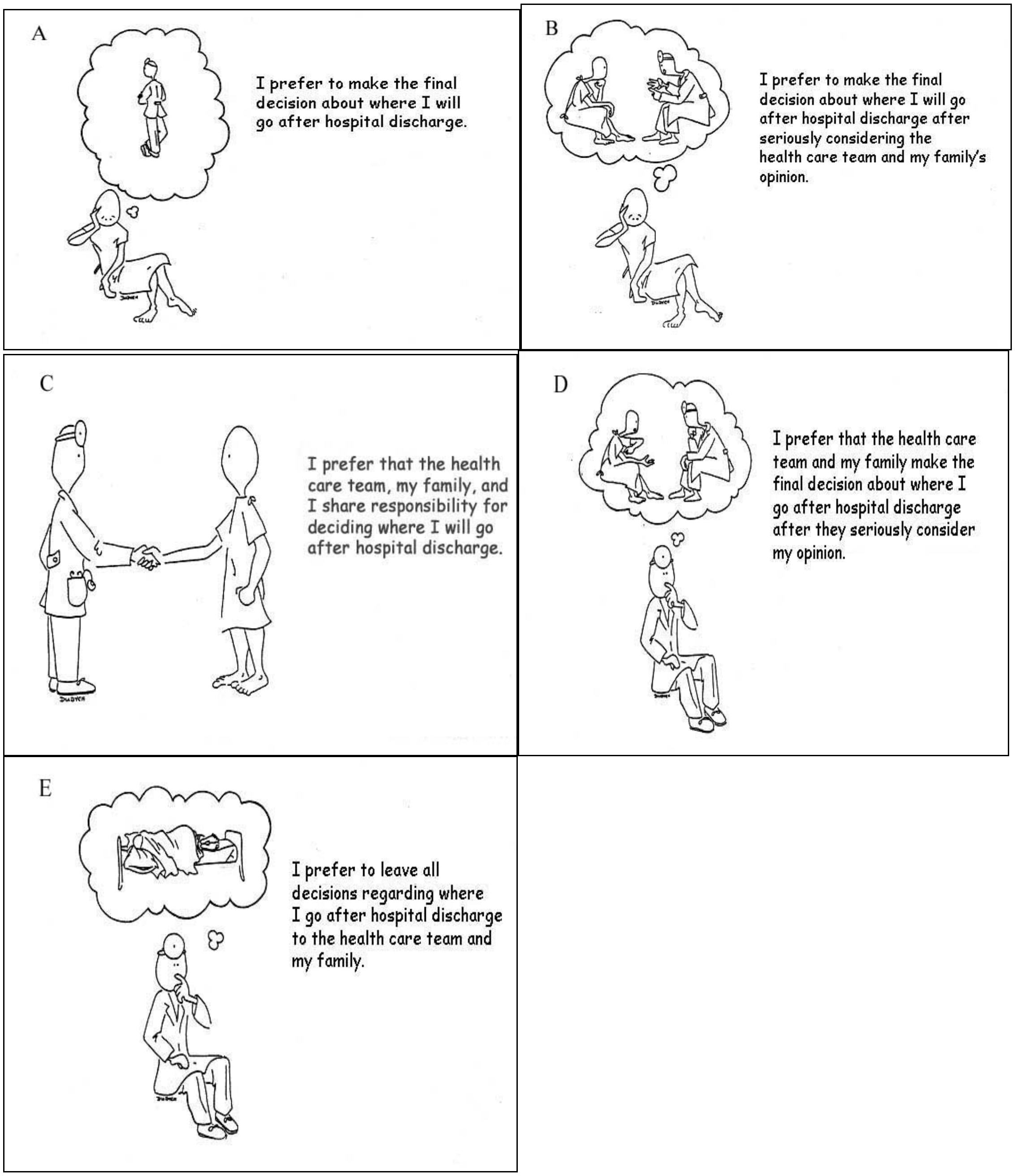
However, data collection occurred very close to the discharge time. Thus, it was unlikely that patients, their family members, or HCTM were likely to change a discharge plan in the final minutes that a patient was in the hospital without a very compelling reason.

Potential Benefits

It is possible that the participants enjoyed interacting with the PI. Often participants in interviews appreciate having the opportunity to share their experiences (Warren, 2001). People may have felt privileged to have others who believed their experiences had merit, and took an interest in their opinions (Warren).

The participants who were nurses and social workers may also have appreciated the opportunity to engage in active research. The hospital is a newly designated Magnet hospital; involvement of nurses in research is an essential component of continuing Magnet designation. Thus, it was beneficial to the both individuals and the organization to be involved in nursing research.

Figure 2, Example of Discharge Destination CPS Cards



*Cards wording for family members and HCTMs reflects their participation and is different than the card wording for older adults (refer to Chapter 3, Table 1).

Card A= active, Card B = active, Card C= collaborative, Card D = passive, Card E = passive

Figure 3, CPS Procedure for Ordering Cards for Metric

Active	Active	Collaborative	Passive	Passive
A	**B**	**C**	**D**	**E**

CPS Cards

Example of presentation of procedure to a participant: Please think about the decision you are currently making about leaving the hospital. As you thinking about this decision I would like to know more about how you want to make decisions. I will show you 10 sets of two card, please select the card that best describes your viewpoint about how you are making the decision to leave.
Step 1: Present every pair two cards and ask the participant to select the card that best represents how much they participated in the decision about leaving the hospital.
Step 2: Count the number of times selections were made.
Step 3: Determine the order the most frequently selected is first, followed by the next most frequently selected until all five cards have been counted.
Step 4: Using the metric table, find the metric order number.
Step 5: Identify the two most preferred levels of participation by categorizing the first 2 cards in the metric.

Step 1	**Step 2**	**Step 3**	**Step 4**	**Step 5**
AB select B				
BC select C	Card A --0 times			
CD select C	Card B -- 1 times			
DE select D	Card C – 4 times	CDEBA	Metric #8	Collaborative-Passive
AC select C	Card D-- 3 times			
BD select D	Card E-- 2 times			
CE select C				
AD select D				
BE select E				
AE select E				

Control Preferences Metric

1	ABCDE	7	CDBEA
2	BACDE	8	CDEBA
3	BCADE	9	DCEBA
4	BCDAE	10	DECBA
5	CBDAE	11	EDCBA
6	CDBAE		

Table 1, Card Sort Choices: Patient, Family, HCTMs

	CPS Statements for Patient, Family, and HCTMs		
	Patient	Family	HCTM
Card A	I prefer to make the final decision about where I will go after hospital discharge.	I prefer that I make the decision for (insert patient name) about where they will go after hospital discharge.	I prefer that I make the decision for the patient about where they will go after hospital discharge.
Card B	I prefer to make the final decision about where I will go after hospital discharge after seriously considering the health care team's and my family's opinion.	I prefer to make the final decision about where (insert patient name) will go after hospital discharge after seriously considering the health care team and (insert patient name) opinion.	I prefer to make the final decision about where the patient will go after hospital discharge after seriously considering my patient and their family's opinion.
Card C	I prefer that the health care team, my family, and I share responsibility for deciding where I will go after hospital discharge.	I prefer that (insert patient name), the health care team, and I share the responsibility for deciding where they will go after hospital discharge.	I prefer that my patient, their family, and I share the responsibility for deciding where they will go after hospital discharge.
Card D	I prefer that the health care team and my family make the final decision about where I will go after hospital discharge after they seriously consider my opinion.	I prefer that (insert patient name) and the health care team make the final decision about where ____ will go after hospital discharge, but that they seriously consider my opinion.	I prefer that my patient and their family make the final decision about where they will go after hospital discharge, but that they seriously consider my opinion.
Card E	I prefer to leave all decisions regarding where I will go after hospital discharge to the health care team and my family.	I prefer to leave all decisions regarding where (insert patient name) will go after hospital discharge to them and the health care team.	I prefer to leave all decisions regarding where the patient will go after hospital discharge to the patient and their family.
Pick 1 card Family	I prefer that my family make all decisions regarding where I will go after hospital discharge.	I prefer that our family make all decisions for (insert name) about hospital discharge.	I prefer that my patient's family make all decision about hospital discharge.

Table 2, CPS Control Preferences Metric

Control Preferences Metric *	
1	ABCDE
2	BACDE
3	BCADE
4	BCDAE
5	CBDAE
6	CDBAE
7	CDBEA
8	CDEBA
9	DCEBA
10	DECBA
11	EDCBA

*1 represents the most active end of the decision-making metric and 11 is the most passive.

Table 3, Study Timeline

Timetable for Project Activities	**Months**													
Activity	12/05	1/06	1/06	2/06	3/06	4/06	5/06-12/06	1/07	2/07	3/07	407	5/07	6/07	7/07
Proposal Defense	X													
Proposal to University IRB	X													
Proposal to Boone Hospital Center IRB	X													
Begin data collection		X												
Prepare recruitment materials			X											
Meet with Directors of Nursing, Case Managers, and Social Workers			X											
Attend staff meetings			X											
Hold research meetings every 2 weeks with advisor			X	X	X	X	X							
Recruit participants							X							
Collect data							X							
Transcribe audiotapes							X							
Analyze qualitative data							X	X	X	X	X			
Enter and clean quantitative data							X	X						
Analyze quantitative data							X	X	X					
Write dissertation										X	X	X	X	
Defend Dissertation														X
Final changes post defense														X
Dissertation to Graduate School														X
Plan to graduate														X
Prepare manuscripts														X
Report results to participating organizations														X

CHAPTER 4

Findings

This study employed mixed methods that combined semi-structured qualitative interviews with quantitative questionnaires that described how hospitalized frail older adults, their family, and health care team members (HCTM) made discharge destination decisions. Specifically the design enabled the investigator to describe three specific aims: (1) the preferred level of participation (LOP) in the discharge destination decision of (a) the frail older hospitalized adult, (b) the same older adult's family member, and (c) the HCTM most involved in the decision; (2) the extent that congruence between preferred LOP and actual LOP about the discharge destination decision occurred for the same individuals; and (3) participants' perceptions of the discharge destination decision.

Sample

The study took place in a medical unit of a tertiary care private hospital. The overall recruitment goal was 20 older adults, 20 key family members, and 20 HCTMs interviews. Study recruitment ended when redundancy was reached. Within 5 months it became apparent that a larger pool of potential participants was needed for recriutment. At that point in the study, 2 triads were enrolled and the recruitment rate was 10%, meaning 2 triads were enrolled out 17 eligible patients. Institutional Review Board approval was obtained and recruitment of medical patients on two additional units, 3000 and 3100 Cardiac Units, of the same hospital; began 6 months after the initial recruitment was started.

Throughout the study, there were numerous challenges to recruitment including potential participants who declined to participate (*n*=54, 73%), agreed to participate but were discharged before they could be seen (*n*=9, 12%), or suffered an acute change in condition resulting in death or transfer to an Intensive Care Unit (ICU) (*n*=3, 3%). Exclusion criteria were verified with staff prior to staff asking the patients if they would agree to see the investigator. However, occasionally patients with known exclusion criteria would inadvertently be asked by staff if they wished to participate. Those patients had dementia or delirium (*n*=2, 3%), came from a nursing home (*n*=3, 4%), or had no family or fictive kin (*n*=4, 5%). The investigator discovered the patients who did not meet criteria during the initial explanation of the study and did not enroll them. Overall study enrollment rate was 17%.

There were 11 complete triads of who met the inclusion criteria. There were three incomplete triads. In one, a family member alone was interviewed. The husband of the older adult asked to be interviewed first because he was going to unavailable for several days. This was done after reminding him that if his wife did not meet the inclusion criteria, his interview would not be used. After his interview, his wife required emergency surgery and a prolonged intensive care stay, making her ineligible for the study. Two other incomplete triads were due to unavailable family members after the patient interview was completed. In one situation, the older adult was interviewed and her husband agreed to be interviewed but lived in another community. A time was arranged when he would be present but he arrived early and could not stay for the appointment. His wife was discharged to a nursing facility the next day, thus contact with him was lost. In the other situation, after the older adult's interview was completed, she made the decision not to tell her family or friend that she was hospitalized. There was information that was meaningful in both patient interviews, therefore the interviews were retained and the involved HCTMs were interviewed. There were 13 triads enrolled in the study, of which 11 were complete and 2 were incomplete triads.

Sample Characteristics

Demographic Characteristics of Frail Older Adults

The mean age of frail older adult participants (*n*=13) was 84 (Table 4). The majority of participants (*n*=12, 92.3%) were between the ages of 72-89, most were female (n=8, 61.5%), and Caucasian (*n*=12, 92.3%). Older adults were admitted to the hospital for a variety of problems: acute infection (*n=4*, 31%), neurological disorders (*n*=3, 23%), and cardiac disorders (*n*=3, 23%), among others. The majority of participants were well educated; six (46.2%) reported having attended at least some high school. Most of the older adults were married (*n*=8, 61.5%) and living with someone else, either a spouse or child (*n*= 9, 69.2%). Prior to hospitalization, eight (61.5%) older adults did not report receiving assistance from the person they lived with. However, for those who did receive assistance, more received help with instrumental activities (IADL) of daily living than with activities of daily living (ADL) (Table 5).

Short Mini Mental Status Exam (SMMSE). The SMMSE was used rule out dementia in the participants. To be included in the investigation, frail older adults had to achieve a SMMSE score of ≥ 3, which was the point that the SMMSE performed similarly to the Folstein Mini Mental State Exam with a cutoff of ≤ 24. In this investigation, Cronbach's alpha test for internal consistency for the SMMSE was 0.624 which is low, however this was not unexpected because of the small sample size (*n=13*). The average total SMMSE score was 4, with a range from 3-6. Higher scores denote no cognitive impairment. Patients who otherwise met study inclusion criteria but who were clearly demented or delirious were not asked to participant. Only one potential participant, after agreeing to participate and signing the consent, did not meet the SMMSE cutoff score and had to be excluded.

Frailty phenotype scores. The frailty phenotype was used to identify the presence of clinical or preclinical frailty in community dwelling adults (Fried et al., 2001). The minimum requirement to qualify for inclusion in the study was frailty score ≥ 2. The mean frailty score was 3.7 (Median=4, Range=2-5). Specific elements of the Frailty Phenotype included weight loss, depression, kilocalories expended, walk time, and grip strength. The instrument was designed to be used with a community-dwelling group; therefore for items that required recall of activity such as kilocalories expended and questions about depression, participants were asked to consider how they felt during their last week at home. Patients in hospitals have such low activity level that this approach was taken as an attempt to mitigate forced inactivity in the hospital. All other items (weight loss, walk time, and grip strength) were actual measurements.

Just six (46.2%) participants had unintentionally lost ≥10 pounds in the past year. Eleven (84.6%) felt "everything was an effort," eight (64.5%) "could not get going," and six (46.2%) expended less than 270 kilocalories per week for women and 383 kilocalories per week for men. Equal numbers of men (*n*=3, 60.0%) and women (*n*=3, 37.5%) reported weight loss in the past year. The same was true for the depression screening statement "I felt everything I did was an effort;" five men (100%) and six women (75%) concurred with the statement. However, more women (*n*=6, 75%) than men (n=2, 40%) concurred with the depression screening statement, "I could not get going." An equal number of men (*n*=3, 60%) and women (*n*=3, 37.5%) reported low kilocalories expended in the past week.

None of the thirteen participants were able to pass the timed walk test. Of those, eleven (84.6%) could not complete the walk test because they were on fall precautions and two (15.4%) did not meet the cutoff time for walking. Only women (*n*=2, 25%) were able to do the timed walk. Among men and women who did not complete the walk test, one (9%) was severely disabled due to a past stroke, three (27%) had been on bedrest for longer than one month, one (9%) could not stand without severe back pain, two (18%) had been admitted for falls leading to injury, one (9%) was vision impaired, and one (9%) had severe neuropathic pain in the feet. The remaining two (18%) did not have serious disability that would have impeded walking, but were also on fall precautions (meaning that were deemed to be at risk for falling) and exposing them to the risk of a timed walk would have been imprudent. Those who had a condition that did not allow them to walk or were at risk for falling failed the timed walking test and were given a positive score for that frailty item (Table 6).

It was anticipated that there would be older adults who could not complete the timed walk test due to frailty. However, it was not anticipated that 11 of the 13 (85%) older adults in the sample would not be able to complete that section of the test. The number who could not walk or could not safely walk was an indication of the profound frailty of the sample, which the measure was intended to identify.

The final item in the Frailty Phenotype measure was grip strength. Eleven (84.6%) of frail elders did not pass the grip strength test. Overall more women (*n*=8, 100%) than men (n=3, 60%) had poor grip strength. Grip strength was a measure that was stratified by body mass index (BMI) quartiles and gender. For each quartile of BMI, an expected grip strength value was given, if the actual measured value was below this number; the older adult was positive for low grip strength criteria. Three measures were taken with the older adult's dominant hand using a calibrated dynamometer. The values were then averaged to obtain a final measure (Table 6).

Demographic Characteristics of Family Members

The mean age of family participants (*n*=12) was 71 (median=74, range=46-88). There were equal numbers of males and females. As with the older adult, 11 (91.7%) were Caucasian and one (8.3%) was African American. The participants were well educated, five (41.7%) finished high school and the remainder had completed college. Eleven (91.7%) family members were married. Slightly over half, or seven (58.3%) were spouses of the older adult and five (41.7%) were children (Table 7). There were discrepancies in how much help with daily life older adults believed they received and how much family members believed the older adult received. For all ADLs except toileting, family members reported that older adults had slightly more help than the older adults reported (Table 5).

Demographic Characteristics of HCTMs

HCTMs were employed on three different clinical areas (units). Four registered nurse outcomes coordinators and two social workers were employed full-time on the 2000 Medical Unit, which had the capacity for 42 patients. Three of the four outcomes coordinators and both social workers were interviewed for this investigation. The others were not interviewed because they did not have patients enrolled in the study. The 3000 Medical Cardiology unit employed two outcomes coordinators and one social worker. This unit had the capacity for 30 patients. One of the outcomes coordinators was interviewed for this investigation and the other did not have patients enrolled in the study. The 3100 Medical-Surgical Cardiology. That unit also employed two outcomes coordinators and one social worker and had the daily capacity for 29 patients; again one outcomes coordinator was interviewed and the other did not have patients enrolled in the study.

There were a total of 13 interviews completed on the three units, with seven different HCTMs participating. Eleven (84%) of the older adult participants were patients on the 2000 Medical Unit, one (7%) was a patient on 3000 Medical Cardiology, and one (7%) was a patient on 3100 Medical-Surgical Cardiology. There were a total of five outcomes coordinators and two social workers who worked with these older adults and participated in the investigation. Four of the seven HCTMs (57%) were interviewed once and the remainder were interviewed more than once for different patients. One outcomes coordinator was interviewed four times, another outcomes coordinator was interviewed three times, and a social worker was interviewed twice.

Outcomes coordinator nurses participated in nine (69%) of the interviews and social workers participated in 4 (31%). The mean age of the HCTMs was 47, (median= 47, range=40-57), six (86%) were females, and all (100%) were Caucasian. Four (57%) had stayed in their current position for over 5 years (Table 8).

Answers to Study Aims

This investigation focused on describing how frail older hospitalized adults, their families, and HCTMs made decisions about hospital discharge and also how congruence or lack of congruence about the decision impacted decision-making by the same triad. The interviews with hospitalized older adults, their families, and HCTMs involved in their care, allowed the investigator to more fully explore not only congruence, but the issues and problems that occurred for frail older adults and their families as decisions were made about hospital discharge.

Study Aim #1

The first study aim was to identify the preferred LOP in the discharge destination decision of (a) the frail older hospitalized adult, (b) the same older adult's family member, and (c) the health care team member most involved in the decision.

Control Preferences Scale

The preferred LOP in the discharge destination decision was measured using the Control Preferences Scale (CPS) (refer to Figure 2, chapter 3). Using a 5-card fixed order method, every possible combination of pairs was compared by the participants. This method required participants to make a total of 10 paired comparisons by sorting a series of five cards (ABCDE). The cards were presented in a fixed manner two at a time (AB, BC, CD, DE. AC, BD, CE, AD, BE, and AE).

Each card had a description of the decision under consideration and a cartoon that visually described it (Figure 2). The letter was concealed on the back of the card so that it would not influence the participant. The participant was shown each set of card pairs, starting with pair AB, and the participant was then asked which one of the two cards best described the LOP in decision-making that he or she preferred. After each selection was made, the investigator wrote the selection down. Each subsequent card pairing was handled the same way until selections were made about all 10 pairs. This method resulted in a final ordering of cards by the participants chosen preferences on a 1-11 ordinal metric of valid scores. The metric represents decision-making preferences on a continuum from very active (ABCDE, metric 1) to very passive (EDCBA, metric 11) (Table 9).

Card order validity. There were card choices that did not fall on the valid orders present on the metric; according to Coombs (1964) these data must be discarded. However, Degner (1997) developed an alternative method allowing data that do not fall on the metric to be retained for analysis. This method will be described in a later section entitled, “Two Most Preferred Levels.”

The number of card orders that did not fall on the metric varied by frail older adults, family members, or HCTMs. Overall for the entire sample (older adults, family members, HCTMs) 66% of the card orders (*n*=25) fell on the metric. For the CPS scale to be valid Coombs (1964) identified that 50% plus 1% of the card orders must fall on the metric and there must also be a reverse permutation of a card order. This meant that an opposite card order had to be present, e.g. a reverse permutation of

ABCDE is EDCBA. For the present study validity criterion was met for frail older adults, family members, and HCTMs.

It was also necessary to review validity of the CPS scale at the individual level of frail older adults, family members, and HCTMs. The wording of the CPS cards for each member of the triad was parallel but slightly different. There were 13 frail older adults that completed the CPS, of those, five (39%) made selections that were on the metric, but there was not a reverse permutation of card order. There were 12 family members that completed the CPS, of those, eight (67%) were on metric but there was not a reverse permutation of order. Finally, there were 13 HCTMs interviews, of those, 12 (92%) were on the metric and there was a reverse permutation of order. Of the three sets, only the HCTMs met both of Coomb's (1964) criteria for validity of the card procedure. Because of the number of cards that were not on the metric, it was necessary to proceed to the procedure developed by Degner (1997) to identify the two most preferred LOP, as a way of retaining data that would have been removed using Coomb's criteria. The next two sections will address how card order and the two most preferred LOPs were identified.

Determining CPS card order. After the participant completed the CPS scale, the investigator counted how many times each card had been selected by the participant. For example, if Card A had been chosen zero times, Card B one time, Card C four times, Card D three times, and Card E two times, then the card order would be CDEBA, which is number 8 on the metric (Figure 3). There were also times when participants chose cards an equal number of times. For example, if Card A had been chosen two times, Card B two times, Card C three times, Card D three times, and Card E zero times, there was no clear order to the cards because cards A and B had been selected an equal number of times, as had Cards C and D. To break such a tie, the card subset that included both cards was reviewed by the investigator. The one card selected over the other in that pair of cards would be chosen to occur before the other in the card ordering. An example of this process is, if card A and card B were compared by the participant and card B was chosen, card B would come before card A in the final card order (Figure 4). Although all attempts to reconcile differences were made, there were times when the card order represented was not on the metric, which means that the card order was not one of the 11 recognized orders. Those cards were retained by identifying the two most preferred levels.

Two most preferred levels. After identifying a card order for each CPS completed, each card order was reviewed and the first two selections representing the two-most preferred LOPs were identified for each participant. Next, the control preferences metric was broken down into six categories representing active-active (AB, BA), active-collaborative (BC), collaborative-active (CB), collaborative-passive (CD), passive-collaborative (DC), and passive-passive (DE, ED) as identified in Degner’s procedure of using the two most preferred LOPs. The cards were then categorized using a six-item categorical scale instead of the 1-11 ordinal metric. One older adult had an active-active (AA) preference for decision-making, three had an active-collaborative preference, four a collaborative-active preference, three collaborative-passive preference, and one passive-collaborative preference (Table 10). This was further delineated into three broader categories: Of the 13 older adults, four had an active preference, seven had a collaborative preference, and one had a passive preference (Table 11).

Family members' scores were more similar to the older adults' than were HCTMs' scores. Two family members had an active-active (AA) preference for decision-making, one had an active-collaborative (AC) preference, three had a collaborative-active (CA) preference, three had a collaborative-passive (CP) preference, three had a passive-collaborative (PC) preference, and none had a passive-passive (PP) preference. When categories were further delineated, three family members had an active preference, six had a collaborative preference, and three had a passive preference (Table 11).

HCTMs' scores were quite different than either older adults' or family members'. One HCTM had an active-active (AA) preference for decision-making, two had a collaborative-passive (CP) preference, five had a passive-collaborative (PC) preference, and four had a passive-passive (PP) preference. When categories were further delineated into three broader categories, one HCTM had an active preference, two had a collaborative preference, and nine had a passive preference. (Table 11)

Overall, older adults and family members were more similar than were older adults and HCTMs or family members and HCTMs. Older adults and families had more collaborative preferences for decision-making. HCTMs showed a strong preference for passive decision-making (Table 11).

Family only as a decision choice. After the CPS procedure was completed, participants were asked to view one additional card with the statement, "I prefer that my family make all decisions about hospital discharge," and answer yes or no. The card was used to identify participants who wanted their family members to make all decisions regarding discharge destination from the hospital and was added because the CPS cards do not include that possible choice. The card was answered yes by a minority of participants: four (30.7%) of older adults, five (41.6%) of family members, and one (7.7%) HCTMs. The majority (*n*=8, 61.5%) of triads had no participants in them who wanted family members to make the destination decision. Eight percent or one of the triads had all three participants who wanted family members to make the decision, three (23%) had two members, and one (8%) had one member who wanted family members to make decision.

Card orders not on the metric. Each card order that was not on the metric was reviewed, comparing the first two preferences e.g. passive-collaborative, of the closest card order on the metric to the card order not on the metric. This comparison was done to identify if there were still differences between the card sets when comparing the first two preferences of card orders that were and were not on the original 1-11 metric. For the older adult, this resulted in only one set of the two most preferred LOPs differing out, of the eight that were not on the metric. Four family members' card selections were not on the metric. When compared, two of the four had differences in their two most preferred LOPs. Only one HCTM selected a card order not represented on the metric. This card order did not match the two most preferred LOPs of the closest metric ordering (Table 12). In total, 4 members of the triad had two-most preferred levels that did not fall on the 1-11 metric for valid card orders.

Decision Preference and Sets of Triads

The CPS data were reviewed to analyze whether different triads (older adults, family members, HCTMs) used a specific preferred LOP more than the other triads. A further purpose was to identify whether there was pattern of participation that occurred between them. A series of 2x2 matrices were produced following the same analysis reasoning described in earlier sections.

Comparing revised CPS metric. The 2x2 matrices were constructed from the CPS data using categories (1-6) and not ordinals on the metric scale (1-11). The purpose of the matrices was to look for a consistent pattern between (a) family members and HCTMs, (b) family members and older adults, and (c) older adults and HCTMs. There was no evidence in the matrices to suggest there was a pattern present (Tables 13, 14, 15).

Comparing every two preferences. There were four card orders that were not represented on the revised metric. In order to include these data from the four card orders, data were ordered by every subset of two preferences for decision-making. Once again 2 x2 tables were constructed looking for a consistent pattern of every two preferences as described in the previous matrices. Again, no consistent pattern was identified (Tables 16, 17, 18).

The 2x2 matrices were another way to look at these complex data to identify patterns of LOP between the different older adults, family members and HCTMs. There was no pattern of participation detected between the three.

Study Aim #2

The second study aim was to identify that congruence occurred between preferred LOP and actual LOP about the discharge destination decision for the same individuals described in Aim #1.

Individual Congruence

Congruence was measured by looking at discrepancies between participants' preferred and actual levels of decision-making participation. After completing the card sort, participants were asked to choose the card that best described the LOP they actually experienced in the decision about hospital discharge destination. Each card A, B, C, D, or E, was given a numerical value 0-4. To obtain the measure of discrepancy, the first choice from the card sort (the first letter in the card order) was subtracted from the card denoting the actual LOP in the discharge destination decision. Actual scores ranged from 0 to 3 or 0 to -3. Scores of 0 denoted perfect agreements between the preferred LOP and actual LOP. The further a score was away from 0, the greater the discrepancy between preferred and actual LOPs. Negative scores denoted that a more passive LOP was preferred than actually taken, and positive scores denoted that a more active LOP was preferred than actually taken. For example, in card order CDBAE, the preferred LOP was C. If the participant chose an actual LOP of E, there was a -2 step discrepancy, indicating that a more passive role was assumed than what was preferred (Figure 4).

Forty-six percent of the older adults (*n*=6) were more passive than they would have preferred, 31% (*n*=4) were more active, and 23% (*n*=3) followed their preference for LOP. However, just 8% (*n*=1) of family members were more passive than they would have preferred, 17% (*n*=2) were more active, and 75% (*n*= 9) followed their preference for LOP. Lastly, 23% (n=3) of HCTMs were more passive than they would have preferred, 23% (*n*=7) were more active, and 54% (*n* = 3) followed their preference for LOP (Table 19).

Congruence Between Triads

Again a series of 2x2 matrices were developed to identify patterns of preferred and actual decision-making LOPs between different triads (older adults, family members, HCTMs). Additionally, a matrix was developed to identify whether those who were more frail had a pattern of using a more passive LOP.

Comparing preferred LOP. The matrices in this section showed a pattern of responses indicating that family members preferred a collaborative LOP (card C) and HCTMs preferred a more passive (card D) LOP. A similar pattern emerged (collaborative and passive) for older adults and HCTMs. But no such pattern emerged for the family members or older adults. However, HCTMs were in general more passive than family members or older adults (Table 20, 21, 22).

Actual LOP scores. Another set of 2x2 tables were analyzed to look for a possible relationship between actual LOP between (a) family members and HCTMs, (b) family members and patient, and (c) patients and HCTMs. These data showed a pattern of participation by family and HCTMs; if the family member was collaborative (card C) then the HCTM was more passive (card D). No such pattern emerged for older adults and HCTMs or the family members and older adults (Tables 23, 24, 25).

Frailty and preferred role. Of concern was whether older adults who were more frail were more likely to have a collaborative or passive decision-making preference. There were two older adults who scored at the top of the range of frailty and both of them had active preferences for decision-making. There were six other older adults who had frailty scores of 4. Four of those older adults preferred a collaborative LOP and two others preferred an active level. There were four others who had a frailty score of 3; of those only one preferred an active level, two preferred a collaborative level, and one a passive level. Once again, no clear pattern emerged, but there was a tendency (58.8%) for those who were more frail to select an active or collaborative LOP (Table 26).

Congruence Between Members of Sets of Triads

Congruence at the individual level was conceptualized as agreement between preferred and actual LOPs, but congruence for the purpose of this investigation also meant agreement between the older adult, family member, and HCTM in a triad. The 95% confidence interval (CI) for achieving perfect congruence among all members of a triad was 2 to 48% (0.02 -0.484). This very wide CI was in part due to small sample size. However, the result also led the investigator to conclude that congruence was more than a numerical measure of agreement, either individually or as members of a triad.

To further elucidate issues associated with how older adults, family members, and HCTMs worked together to achieve congruence, the discrepancy scores for each triad was reviewed to identify whether triads that had more members with individual discrepancy voiced more disagreement or concern about the discharge destination decision in the interview (Figure 6). The discrepancy scores for each triad were clustered and reviewed together. There were four different sets that were categorized by numbers of discrepancies within each triad: (a) none of the three members had a discrepancy (*n*=2 triads, 15%), (b) one of the three did (*n*=4 triads, 31%), (c) two of the three did (*n*=4 triads, 31%), and (d) all members did (*n*=3 triads, 23%). The analysis included: (a) reviewing discrepancy scores, (b) reviewing two most preferred LOP for decision-making, and (c) analyzing interview data for each triad, looking for information that would contribute to understanding about how congruence was achieved or what specific concerns may have led to incongruence. There were four sets of triads identified, based on the number of members within each triad that had individual discrepancy.

No discrepancy between members. There were two triads in which all three members followed their individual preference for LOP in the decision about hospital discharge. Each member of both triads had discrepancy scores of 0 and also had collaboration as either their first or second preference for decision-making (Table 29). The first of these triads included a wife as the family member. In this triad the wife and older adult were aligned in their responses about going home, both recognizing home as the only acceptable discharge destination. The HCTM in this triad was also comfortable with their decision for the older adult to go home.

In contrast, the second triad in which all three members followed their preferences included a mother and her daughter who were not as cohesive. The mother perceived that her daughter absolutely wanted her to go home with her. She characterized her daughter's position in the following way: "They don't want me in a nursing home. I guess I will end up with them." However, the daughter did not entirely share her mother's viewpoints. She was willing to have her mother live with them for a short time, but identified that her mother would have to go to a nursing home if she could not regain independence. The daughter's thoughts were illustrated by the following, "I think she knows she would have to [go to the nursing home]. It would depress her but I think she knows she would not have much choice." The daughter went on to address specific concerns related to privacy of her and her husband, as well as concerns about taking care of her mother. There was lack of clarity between the two about the best approach to take. The HCTM in this triad also experienced difficulty getting an accurate picture of what the older adult and her daughter wanted to do at discharge,

> "Well I get a stronger sense from the daughter that she wants her to come and live there than I do from the patient. I won't say that it is a really strong sense, well I don't know. It is truly just a sense that I have—it's nothing the daughter has really verbalized. It's that she is responsible for her mother, she is going to do the best thing for her mother—even though that might not be the most comfortable thing for either one them."

The second triad, when compared to the first, lacked cohesiveness. The members of the triad did not actually know the concerns of the other members about the hospital discharge of the older adult. There was the sense that mother and daughter were not communicating fully with one another about this impending change in their living situation. One triad achieved complete congruence at the individual level that translated into congruence of the triad, but the other did not. The situations for the two triads were different. In one, the family member was a spouse and the patient was returning home. In the other, the family member was a daughter and the patient was going to a new living situation with her. It was possible that going back home to an established living situation with a spouse was a clearer decision than making a destination change to either a nursing home or a child's home after leaving the hospital.

Discrepancy in one of three members. This set was comprised of four triads in which two of the three members followed their individual preference for LOP in the decision about hospital discharge. In three of the triads older adults did not follow their level of preference for decision-making and in one triad the HCTM did not follow their preference. In all four triads older adults chose active LOP as their first or second choice. Three triads had more than one participant who preferred an active LOP. There was no clear pattern between LOP and discrepancy between preferred and actual LOP. One triad member preferred to be active and actually was collaborative, another preferred collaborative and was active, and the third preferred collaborative and was passive (Table 30).

One of the four triads of this second set included a father and son; three included older adults and their spouses. The father and son pair included a very frail, elderly man who had not been out of bed for months. His goal was to go to the nursing home, receive rehabilitation, and go home. He had a strong desire to stay involved in decision-making and actually had a more collaborative LOP than preferred, meaning he was more passive than he wanted. His son preferred a collaborative-passive LOP and had assumed a collaborative LOP. He was willing to do what his father wanted with some limitations as described by this statement, "He just has to be in good enough health to go home and take care of himself [*sic*] without risk of injury." The HCTM agreed that going to the nursing home and then possibly home was a reasonable plan. There was no sense of disagreement between the three, merely the essence of trying to untangle the complex care required for an older, very frail man. The collaborative LOP of the son and the passive LOP of the HCTM may have been complementary to the father's desire for a more active LOP, leading to more congruence about the discharge destination decision.

The other three triads consisted of older adults, spouses, and HCTMs. Of those three, two triads had achieved congruence. One of the three triads that achieved congruence included a wife who was the sole caregiver for the patient. The patient was quite debilitated and was unable to walk without severe pain. The second included a husband who was also the primary caregiver for his wife, but had hired assistance for her personal care. The spouses of both of these older adults were committed to bringing them home. They understood the home situation would be difficult to manage due to the frailty of their spouses, but they were committed to bring them home. This commitment to going home and nowhere else was described by the wife of a patient: "... I don't foresee us making any other change. I think there will be help. But it depends on how his health goes. But I don't foresee him doing anything else [but going home]."

Her husband also was committed to going home and had asked the doctor to discharge him that morning. He no longer wanted to be in the hospital and believed he could receive needed care at home. Both of the spousal pairs in this set of triads wanted their husband or wife to go home and believed they would continue at home for as long as possible. Additionally, neither patients nor spouses in these two triads talked about having their children assist them at home. This comment reflected how involvement of their children was viewed by both triads, "Well, because I don't want to impose on them much. I try to take care of it by ourselves with what other help I can get."

The HCTMs were supportive of the plans of both spousal pairs. Their role was very straightforward and included setting up needed care and services. This comment is representative of the role that the HCTMs played:

> "My role is to assess the home situation and pay attention to her physical abilities, and what support systems she has in place to determine a discharge plan for her once she is was [*sic*] ready to leave acute care."

The third wife and husband pair was quite different from the other two; they did not achieve congruence as a triad. The patient had a back injury that had left him bedridden and in severe pain. His physical condition was much less debilitated than the other two patients in this set of triads. He was preferred an active LOP and was very certain that his wife would care for him at home as illustrated by this comment: "That is the main decision, to go back home and her to take care of what needs to be done." The wife on the other hand, had a different viewpoint of what may happen at discharge, as illustrated by this comment:

> "Of course we prefer to go home. I want to take him home. It is my understanding that skilled nursing is up on the eighth floor of the hospital and if he required any skilled nursing we talked about it and would prefer to go to the eighth floor and not be moved to another facility."

The HCTM in this triad was taking an active role identifying what coverage was needed by the older adult and how care would be organized. The HCTM recognized that the patient and family may want to take one course of action, but that course may not be possible based on what was available for care and treatment at home. The HCTM's position was illustrated by the following:

> " I don't know if we are going to be able to get him home or not, he is still having a lot of pain. I am not sure he is going to be able to get up and do his transfers, and get to the bathroom. They are worried about Mrs. Black [fictitious name] being able to help him. He weighs 290 pounds. That would be a heavy transfer for one person. The focus has changed from home on IV antibiotics to his mobility."

The actual plan for leaving the hospital was not straightforward and was dependent on the ability of the patient to receive the needed services. The difference between this triad and the others was the complexity of the services required at home and the amount of complex care that would have to be done by family. The relationship between the husband and wife was not the issue, but rather the practicalities of bringing someone home who would be difficult to care for because of his physical size and need for intravenous therapy.

Congruence within this second set of triads took the form of negotiation for the best solution, given what the older adult and their family wanted to do at the time of discharge. There was no overt disagreement between members of each triad. Two of the spousal pairs were very willing to take their spouses home, even though they were frail and required extensive care. However, in the last triad described, the spouse was much more accepting of the need for skilled nursing facility (SNF) care than was her husband. She did not have same strength of belief that home was possible at this time. The HCTM in that triad also questioned that home was going to be an immediate option because of the patient's condition and complexity of care. Overall, triads that contained older adult and spousal pairs were congruent in the decision to go home as long as complex care was not required.

Discrepancy in two of three members. This set was comprised of four triads in which one of the three members followed their individual preference for LOP in the decision about hospital discharge. As with the previous set of triads, there was not a clear pattern of discrepancy. All of the older adults in this set of triads had discrepancies between their preferred and actual LOP. Three of the older adults had a more passive and one had a more active LOP than preferred. There were two family members with discrepancies; one family member had a more passive and one a more active LOP than preferred. There were also two HCTMs with discrepancies. One health care team member had a discrepancy between two different levels of passive decision-making. The other HCTM had an unusual presentation in that she assumed an active LOP but would have preferred a passive (Table 31).

Three of the triads included older adults and their child. One triad included an older adult and spouse. In one these triads, a mother and daughter pair; the mother had been living alone prior to this illness, which was very serious and included a period of delirium. The second triad included a mother who lived alone in her own home in the country, but was assisted by her son. She had a gastrointestinal illness that had left her dehydrated, but without permanent debility. The third triad included a mother, admitted for cardiac illness, who lived with her two children. Her son moved back to the area and built a home so he could care for his mother, and she lived there with her son and daughter. Her daughter worked outside the home and her son was her primary caregiver. The fourth triad included an elderly African American man and his wife. This triad will be described in greater detail at the end this section as members of this triad represent the most extreme example of incongruence found in the study.

As with the previous set, three of the four triads were congruent. The older adults and their children worked well together even though they represented very different pictures of caregiving for a parent. It is worthwhile to note that these were mother-child pairs, not father-child pairs. Two of the three women lived independently and would require care after hospitalization, one planned to go home, and one planned to go to the nursing home if that was needed. The women accepted help easily as illustrated by the comment, “Yes, I will feel better for doing that [going to stay with her daughter]. I need someone to help until I get stronger, until I can get on my own feet.” Her daughter was strongly in favor of her mother coming to her home, as evidenced by this statement when asked about discharge destination options: “No, no she will come home with me.” There was no question as to where her mother would go after hospital discharge.

Another woman recognized her need for help and had a plan to go to the nursing home. She was comfortable with that decision and her son was in agreement. Furthermore, she was not opposed to living in a nursing home, but would prefer to remain at home as long as possible. Her point of view was reflected in this comment: “Well I would like to go home, but I am so weak and so trembly [*sic*]. I am not walking very good [*sic*]. I think it would be best for me to go to the nursing home.” Her son did not give her physical care, but supported her in other ways such as paying bills and taking care of the farm. He was in agreement with her decision. He also saw the nursing home as a short-term solution until she gained her strength back, as evidenced by his comment, “She more or less she told me she wanted to go to the nursing home. I thought it was a good idea. She wanted to get her strength built back up.” Even though the discharge destinations were different for the mothers and children just discussed, both were in agreement with one another about the best plan.

The final triad that included a mother-son pair had a very different relationship than the other two. The older adult in this triad lived with her two children, who took care of her. When she was asked where she was going when she left the hospital she said to her son’s home. She described living with her children positively, but made comments such as “they put up with me.” Her son was present for her interview; he chose not to leave the room. During her interview there was a positive, almost joking interaction that went on between the two of them. Remarks such as “they put up with them” seemed to fit into their relationship with one another. During his interview, her son described how he cared for his mother: “Well, I have a responsibility of taking care of her like she took care of me. I went out and bought another home so I would have room enough for her and me.” This certainly indicated a desire to keep his mother with him and not in a nursing home.

In all three triads the HCTMs were supportive of the decisions that had been made by older adults and their family members. Most of the plans for discharge from the perspective of the HCTMs focused on getting services to support care in the home or assisting with making plans for a nursing home stay. One HCTM had concerns about the home situation and those concerns centered on the family’s ability to give the older adult her cardiac medications. The importance that HCTMs place on medication safety was demonstrated by the following comment:

> “ I talked to her daughter and she had a long list of concerns and questions. She said Dr. Gray [fictitious name] has been talking to her brother about these things. She said my brother can’t remember all those things when he gets home to tell me…..This raised a red flag, wow I hope her medications are being given appropriately. I am going to go back to the patient and say are you getting your medications, does your son give them to you?”

As in the other two sets, individual level discrepancy did not seem to overtly impact the outcome. There was a sense of communication between each member of the triad. The ability to communicate with one another was the most influential factor in achieving congruence. The children in two of the triads played an active role in helping their parents decide where to go after discharge. One of those two returned to live with children and the other was temporarily moving in with a child. The third triad was a bit different in that the patient wanted to spend some time in the nursing home for rehabilitation and her son concurred with her wishes. She described the need to receive rehabilitation to get stronger, which also was identified in the first set of triads.

In this set of triads, unlike the first set of triads, a parent coming to live with a child for the first time did not create stress. The difference may have been the living arrangement just described was not going to be permanent, while in the first set there was the possibility that arrangement would be permanent.

The triad that follows was the most incongruent of any triad in any of the sets. This triad was worthy of a more in-depth look at how decisions about hospital discharge were made between members. The patient was a very large, frail man, weighing over 290 pounds. He had been bedbound for several months and had a recent of history of multiple hospital admissions, a skilled nursing admission, and a rehabilitation admission that ended because he failed to make progress in his rehabilitation. His wife, who was his primary care provider, was a very small woman and she could not move him in bed or get him up from the bed to a chair. She also described that if he fell, her only option was to call 911 to get him off of the floor.

When the patient was asked where he wanted to go when he left the hospital, he replied, "Got to go home. Nothing wrong at home [*sic*]." His wife saw the situation a little differently than he did. When asked about options other than home, she replied:

> "Jim [fictitious name] wanted to go home and I felt that it was something we could provide for him and we should get him home. After he was home we will see how he gets along. It might be that he will have to have other options, but you know we don't know. He was home I believe it was six weeks it was pretty rough. We didn't have any help like we had planned on having because they were all discharging him and saying he was OK…"

His wife recognized that he might not get along well at home and things might need to change if he remained difficult for his wife to handle and care for. As the HCTM reflected back on her experiences with other discharges with this same patient and his family, she felt little optimism that her recommendations would be seriously considered:

> "I have worked with Mr. Green [fictitious name] and his wife twice in the past couple of months. The first hospitalization I worked with them up to the point that he had a brain biopsy and he was sent off the unit. So, that was a very workable kind of situation. I felt that I kind of assisted them in making some thoughtful decisions about aftercare and helping Mrs. Green [fictitious name] see how overwhelming Mr. Green's [fictitious name] care would be. That was a false premise because when he returned he had already been through our skilled nursing, through Rehab and still was not able to bear weight. He had gone home and failed there. So, when he came back I was less optimistic about how much, how seriously my suggestions would be taken."

Unlike the other triads in this set there was not a sense of oneness of purpose. The patient and his wife were going home, regardless of what was recommended to them by the HCTM. Nonetheless, his wife was not entirely certain she would be able to care for him at home, but had no plans to consider another destination. The HCTM did not think the wife was capable of caring for him at home, but recognized that regardless of her opinion the patient was going to go home. She felt a sense of unease about the decisions being made, but recognized that she could do little about it. The couple received no routine support for daily physical care from their family members and this too concerned the HCTM. The main difference in this triad, compared to the other three triads in this set, was the HCTM felt the need to intervene actively to change the wife's mind. In no other triads did the HCTM so clearly disagree with the discharge plan.

Discrepancy among all members. The fourth set was comprised of two incomplete triads and one complete triad. Within this set all members of incomplete or complete triads had discrepancy scores. The incomplete triads occurred because the family member was not available for participation after the interview with the older adult had been completed. As in the other sets of triads, there was not a clear pattern to the discrepancy scores. Two of the older adults actually assumed a more passive and one a more active LOP than what was preferred. The HCTMs in these triads continued to show a preference for following a passive LOP (Table 31).

There were few similarities between the triads in this set. The first included an older adult who was married. She had been hospitalized for months with cardiac problems followed by a fracture. She was not from the community and wished to leave the hospital in order to be closer to her husband. The second was an elderly woman who had been admitted to the hospital multiple times for injuries due to falling. She had no involved family and had no intention of telling them she was hospitalized. The third included a husband and his wife. She had suffered a devastating stroke 5 years previously and he was the primary caregiver for her, but she also received assistance with personal care and nursing care several times week from the Department of Health and Senior Services, Division of Senior Services (DSS). She was also so debilitated that she was unable to move from her wheelchair without help.

The older adults in these triads were very open to discussion and communication as evidence by this older woman's need to involve her family in her decisions about going home: "I said, 'I want you in on this' and he said 'no that is your decision, you do what you want'. I said 'no, this is a family decision, we all will decide'." She had also expressed concern for her husband, who was becoming tired from having to travel back and forth to the hospital. The older adult was unable to care for herself in any way and made her decisions about what must be done to get the needed care, based on how much hardship she believed she placed on her husband. She described her feeling this way: "I don't like to go out in this shape. It is so hard on my husband to wheel me out and put me in the car.... Most of the time I just stay at home."

Her husband had a similar pattern of concern for his wife. He talked about how she viewed his caring for her.

> " She thinks I was tired. I was having a backache. She was not willing to sacrifice my health. So she would go the nursing home. I really think this is what happened here…. She knows how the good Lord makes things work, he put her in the hospital and I could get my back taken care of. I will be ready when she comes back."

In both of these triads the women were concerned about the health of their husbands. Decisions were made based on their family's needs as well as their own. They wanted to work together to achieve the best possible outcome for all. The HCTMs involved in both these triads identified that their roles were very basic. They gave information to patients and family members about service availability or nursing home placement and also were available to support them as they needed.

Another woman in this set of triads had a completely different view of how she made decisions about discharge from the hospital. She described that she liked to elicit the opinions of others and then decide what to do. However, she did not actively seek to involve her family in her decisions. She explained her position this way, "If he [her son] could do something for me I would be happy to tell him, but I don't see that he can do anything." She generally described herself as someone willing to listen others as reflected in her remark, "….I listen to people and listen to other people. I just have a woman's thing [needing to talk about issues with others] and I would go over it with them. Just to hear what they think and follow it with what I think." There was a lack of consistency in how she approached communication with others and in whom she chose or did not choose to tell she was hospitalized. Had her son been interviewed, there may have been some incongruence in this triad. As it was, only the older adult and a HCTM were interviewed, the HCTM was very supportive of her wishes and was willing to assist her to find the care and services she needed. He saw her as an interesting character and appreciated her desire to be independent.

This fourth set of triads underscores how complex it was to ascertain whether congruence was present among all members of a triad. If any set of triads were going to be incongruent it would have been this fourth set, where none of the members of the triads achieved individual congruence. The strong sense of communication and willingness to consider other viewpoints that were present between the members of these triads certainly appeared to lead to improved overall communication and congruence among all members.

Discrepancy scores summary. When looking at discrepancy scores across individuals in triads, it did not seem to matter how many of the individuals had levels of discrepancy between their preferred and actual LOP in the discharge destination. What seemed to be more pertinent was the compatibility between the decision-making preference LOPs (active, collaborative, and passive) and it's importance in arriving at a workable solution to the discharge needs of the older adult. However, the triad members' willingness to work together and respect one another's decisions also played a role. A sense of respect for the other's autonomy and rights was identified in several triads.

Furthermore, decisions about discharge destination from the hospital may or may not be life-altering. If the older adult was merely returning home to live with a spouse, then dramatic changes in their home situation were not required. However, if the older adult was leaving the hospital to live elsewhere, whether it was with a child or in a nursing home, those decisions were harder to make, more emotionally draining, and less cohesive. Decisions that the HCTMs recognized as potentially hazardous or unsafe were likely to lead to congruence. To understand more about decision-making congruence, data were also analyzed using thematic analysis.

Study Aim #3

The third aim was to describe the participants' perceptions of the discharge destination decision. All data from older adults were analyzed first, followed by family members' data, and last HCTMs data. The themes and subthemes that were identified were analyzed across the three participant triads of older adults, family members, and HCTMs. Data findings were reviewed with the investigator's advisor to verify that findings were plausible and credible.

There were differences between the frail older adults, family members, and health care members in the themes that emerged. Frail older adults considered home their only destination of choice when they left the hospital. However, this finding was not true for either the family members or HCTMs. The family and HCTMs were more concerned with seeking out information and deciding on a workable plan for services and discharge. In the next section, the results of the qualitative inquiry will be reported by frail older adult, family, and HCTM triads. Results of this analysis extended beyond the initial aim of seeking more information about perceived congruence. The analysis allowed the investigator to develop more insight into the elements that affected the discharge destination decision-making process.

Frail Older Adult

Home

Going home was the pervasive theme of the interviews with older adults. For even the frailest older adult, going home was simply what you do when you were well enough to leave the hospital. As one participant said, “It is just what you do. You get out of the hospital and you go home.” There was no question in her mind that this would happen—she would leave the hospital and go home. Even for those older adults who go to long-term care to receive rehabilitation, home was still the ultimate goal. An older adult who had been hospitalized off and on for months continued to see home as his final destination, although his likelihood of returning home was becoming increasingly slim. When asked if home was his final destination he went so far as to say, “Yeah, till we go to the cemetery. That is my final destination, at least here on earth. I have a home in heaven.”

Staying together at home. A subtheme of home was the notion of staying together at home. For those frail older adults who were married or who were in an established living situation with children, it was important to stay together. Older adults identified that they “do what they have to do” to stay at home. Another frail older man, when asked if he envisioned a time when he could not go home, stated, “If we can’t go together [to the nursing home] then you better get the undertaker to take us.” Staying together as a couple was important to some, but others would not go the nursing home just to remain with their spouse. If they could get back to their home, even alone, they would do so. For older adults who relied on spouses and children for day-to-day care, there was an underlying vulnerability and awareness that things could quickly change. If this happened, they would have to leave their homes to go to a nursing home if they could no longer care for themselves or their care became to onerous for their families. The importance of being independent was threaded throughout older adults’ discussions.

Independence

For older adults, being able to get along reasonably well in their current living situation was the meaning of independence. This did not mean being physically independent, but rather described how the older adult worked with and through other people to get tasks of daily life completed. There were several subthemes identified as, (a) “getting the help I need,” and (b) “changing how I do things.”

What defined independence for older adults was the ability to do things for themselves. For many, their greatest desire was to get better so they could take care of themselves and not rely on others. Many of these older adults had received rehabilitation for a previous hospitalization, returned to living alone, and thus were aware of what happens in rehabilitation. Their current situation was seen as temporary, described by this man, “Before long as they get this infection cleared up I can get back to normal, like I was before without any problems.” Another man described losing independence as happening more slowly.

> “There some things you can do and some things you can’t. You don’t lose everything in one day, it takes a week or two. You have to figure out what you got left, to keep those things up or do what you have to do.”

For others, the loss of independence came after fighting hard to regain their functioning and it led to a life that was very different than before their illness. The words of this woman described it movingly,

> “Time ran out, I think they found there wasn’t anything else they could do for me. The doctors said that therapy would not do any good. My stroke was severe enough. I was just paralyzed, just froze, and that was that.”

For older adults, independence was the foundation for returning home. For some, their independence was intact and with a little help from therapy, they would easily return to their homes, able to continue their life as before. For others, gradual losses in their abilities had already been acknowledged and accommodated in day-to-day life prior to this hospitalization. Yet, for other older adults independence had taken on a new form that included getting the help they needed to function at home.

"*Getting the help I need.*" For some, therapy was the help they needed to once again become independent and go home; however, for others, more complex help was needed. Older adults were often optimistic about what could be done at home. Medical procedures such as giving intravenous antibiotics and maintaining peripherally inserted central intravenous catheters seemed to overwhelm some potential caregivers, but not the older adults. Help was often seen as temporary, as this statement characterized, " I just need someone to help until I get stronger, until I get on my own two feet." Who that would be was not always described by the older adult. Those with spouses knew where the help was coming from; however, even that help was not always realistic, as with a large 290 pound man whose wife could not lift him to assist him to the bathroom. The independence of the older adult was dependent on the ability and willingness of the family to give help, resulting in a change in how the older adult did things.

"*Changing how I do things.*" Particularly women, whose life work often involved taking care of others, felt a sting of being taken care of because of their illness, as described by an older woman,

> "I like to take care of myself and other people. Now I can't do it.... One day I thought I would go start dinner. I wheeled myself into the kitchen. I wanted to peel potatoes and couldn't hold the damn potato."

Others have reconciled the possibility they may need to live with their children as described by this woman,

> " No [*sic*] just going to live with the kids if I can't live by myself. I learned to live with that. Straightened it out, so I don't have to worry. I don't want to be there, but the only thing I know is it will be a change in myself."

Still others were not willing to change how things are done to get the help that may be needed such as home health nurses or aides. For those the issue of where they will end was more problematic.

Where I End Up

If going home was not an option, the older adult had to make a decision about where they would "end up." To decide where they would "end up" was an active decision made by the older adult either alone, or more often in concert with the family and the HCTM's guidance and support. Often this decision was predicated on the older adult's independence. The theme of "where I end up" included subthemes of (a) who decides, (b) staying safe, (c) listening to others, and ultimately (d) selecting a nursing home when home was not an option.

Who decides. As older adults were making plans to leave the hospital, the majority spoke about who they worked with to help make decisions. For those who still lived at home with a spouse, the couple talked and decided about discharge. Older adults who were married and had children were very independent of their children. The children gave their opinions, but did not try to force their opinions on their parents and appeared to keep a respectful distance between their lives and the lives of their parents. Parents did not give them information if they did not want the children involved. One single female participant chose not to tell her son she was in the hospital. However, it was more typical for the parent or parents to inform their children of what was happening. The following quote was representative of how couples and their children worked together:

> "Well Andrew [fictitious name] and I have made most of the decisions. We go along with the boys. We listen to them, but that is about it. They don't try to tell us what to do."

Staying safe. For older adults, staying safe was important. However, as will be discussed later in the HCTMs section, older adults were not as concerned about their staying safe as the HCTMs were. Nonetheless, the issue of safety and ability to get around was important to the process of deciding "where I end up." For older adults who had fallen or were at risk for falling, safety became an issue because either they themselves or others believed they could no longer live alone. One older woman described how her daughter viewed her being able to walk and it's importance to her daughter's comfort level about leaving their mother alone,

> "They think that if I am in a wheelchair or using a walker I shouldn't stay by myself. They want me to be able to walk. Even if I was using a walker, if I was able to walk I don't think they would complain too much."

For older adults and their families, the issue of falling and getting hurt was troublesome and made decisions about "where I end up" potentially more difficult.

Decisions about where to end up were particularly hard if the older adult chose not to listen to others who were involved with decisions about discharge.

Listening to others. Older adults were willing to listen to others to a point; this included medical authority. There was recognition by a few older adults that they had the final say in their medical care. That final say included things as simple as choosing not to walk because it was too painful, or recognizing that the pain control strategies ordered for their condition were inadequate and demanding a different approach. One older adult made her decision about which nursing home to live in based in part on the availability of her doctor to care for her in that facility. Medical authority was important to the older adults, including a trust for their doctors and the willingness of doctors to listen to their opinions.

Older adults also spoke of the importance of listening to others, although they recognized that they might ignore what was suggested to them. As one older adult said, “You sometimes know they are right, but you don’t want to give up. Too danged independent I guess.” This viewpoint was shared in part by another older adult who only listened to recommendations for alternative places to live if she agreed with the alternatives. Yet, another older adult knew the time to make a decision was at hand when the hospital days ran out and the HCTM made the suggestion that the current care situation needed to change from acute care to long-term care.

Nursing home. When home was not an option and those who were helping the older adult make decisions were concerned about care or safety, nursing home care became more likely. For those who lived alone and had a temporary reduction in their ability to care for themselves, nursing homes were viewed as stops along the way home, a way to get stronger. They saw the need to get stronger and begin walking again as essential to the goal of returning home. The following comment was representative of the older adult seeking to get stronger in the nursing home,

“…we don’t have a choice. I have to have therapy to get to walking. So many nursing homes don’t have therapy.”

For those who had to go to a nursing home, being geographically close to their home and family was important for them and their family. As one participant who had been hospitalized for weeks stated, “It was amazing how relieved my husband sounds that I will be close to home.”

Older adults knew the nursing home was in their future when they could no longer care for themselves or be cared for by someone else in their homes. The comments made by the participants were often brief, such as the response to the investigator’s question, Can you envision a time when you will no longer be able to live at home? The participant’s response was, “If I can’t take care of myself.” Although the comment was brief, it was not the words she spoke that made her words so poignant, but the sadness in her tone and the resignation in her voice as she recognized that for her, living in a nursing home would eventually become a reality.

Home was the first choice of where to live, but it was also the affordable option. When the nursing home option was considered, older adults also spoke of the expense of living in a nursing home. However, this was a well-educated and astute group of older adults, and they knew that short-term rehabilitation was covered by the Medicare insurance benefit, making short term admission to the nursing home more acceptable. They could receive rehabilitation and then go home without financial liability.

Family

Going home was the pervasive theme for the older adult, but for family members the focus was different. Family members were far more inclined to be concerned about finding out what was wrong, so the illness could be cured or a plan for helping to care for the older adults developed. The needs to advocate for good hospital care, identify ongoing care needs, and organize that care, were the most important elements that emerged from the interviews with older adults' family members.

Finding Out What Is Wrong

For families, the first step in the process of leaving the hospital was to find out what was wrong and have it taken care of. When parents lived alone, children relied on them to tell them they were ill. A few of the older adults interviewed did not have serious illness, but were being treated for short-term problems such as nausea and vomiting or chronic problems such as congestive heart failure. For families of these older adults, the need to find out was not as urgent. The illnesses were chronic and it was a matter of adjusting therapies. But for families of older adults who were suffering from acute intractable pain, neurological problems, acute cardiac problems, or injuries, the need to find out what was wrong and have the problem fixed was more urgent. The daughter of an older woman admitted with acute pain stated the issue this way:

> “The second time she came because of the pain—other things were going on like her bladder infection. Of course that is what they really zeroed in on. Then it was kinda like, OK, she is going to come home and we are going to figure out what is wrong. She will go home. This time it was like what if they don’t find out what was wrong? What if the pain isn’t fixable? Yeh, it has been more of hmm, maybe this was it. I’m not, I guess we have built our hopes up, and we haven’t thought too much. Just the fact that early on she was given some medicine that seemed to be working, and now she is having this attack again.”

There were subthemes associated with the theme of finding out what was wrong which included (a) “advocating for them,” and (b) “pushing for walking.”

Advocating for them. There was a need for family members of the frail elderly to stay involved in the hospital care of the older adult. Both spouses and children advocated equally aggressively for the frail hospitalized elder. The situations that required family members to advocate varied. A spouse of an older adult related this experience with his wife’s care:

> “…in January we were walking with a little hand walker and I turned around to look for something in a drawer and she fell and broke off the ball of her hip. Anyway we brought her down and they put the ball back on. On the 7th we started rehab and we done that until the 17th. It got so bad and it was miserable. We couldn’t go anymore. I told the nurses we couldn’t do anymore. We had an x-ray and it showed that it been out of place this whole time. For 10 days.”

For the older adult and her husband, this situation was only part of a complex series of events that eventually led to her complete disability.

Other older adults and their family members experienced frustration when they perceived that the actions of the physician were not appropriate. A daughter of an older woman admitted for severe back pain described her concerns about how a physician communicated with her mother,

> “… She looked at him and said I am not leaving here until I can walk. He said, “Well what are you going to do?” Luckily the therapist was there and

> was supportive that she can't walk. He said, "Well I am not an orthopedic doctor you will have to work with him." It is so frustrating. He has always been so supportive of my mother. I don't know what caused him to rankle like that."

Physicians were not the only health care providers who were viewed negatively by older adults and their families. Families felt the frustration of the hospital environment that was not always friendly to the older adults. One wife related her aggravation with how her husband's care unfolded,

Decisions made by health care providers in the community sometimes resulted in older adults being unable to continue care at home, which ultimately led to the older adult's readmission to the hospital. This accounting given by an elderly woman as she cared for her very frail husband explained the challenges faced by some:

> "He was at home I believe it was six weeks. It was pretty rough. We didn't have any help like we had planned on having because they were all discharging him and saying he was OK. Physical therapy discharged him and hmm the other folks did not show up. No one but the RN and he was only there three times and on the third visit he said, I am discharging him. This man is fine."

There was tension between the patient, his family members, and the HCTM caused by the need to push the frail older adult, improve physical functioning, follow the regulations associated with health care, and yet respect their inability to tolerate activity. These issues did not compliment one another but created tension between those participating in decisions. Nonetheless, for hospitalized older adults who wanted to go home, the main task they had to attend to before leaving was resumption of physical activity, particularly walking. It was often part of the advocacy role of the family to push for physical activity of the frail older adult.

Pushing for walking. The ability to get up and walk was an important function for frail older adults. Retaining or regaining the ability to walk meant the difference between going home or going to a nursing home. As described in the previous section, family members did not always want their hospitalized frail older adult to be pushed to activity that was uncomfortable. However, there was another family viewpoint that emerged as well, the need to get the older adult up and walking so they could eventually return home. A frail older woman's husband described how he viewed the importance of walking,

> "It will help strengthen her. When you have been lying in a hospital bed for a week, you will lose your ability to use your muscles. That was what we are faced with, that is why I want them to walk her morning and afternoon here."

He recognized that unless she was able to walk, his ability to take her home would be seriously limited. For other older adults who have been unable to walk, there was a need to go to the nursing home. Even the most dedicated family members recognized that if the older adult lost their ability to walk that nursing home care would be the only option.

Throughout the themes of "finding out what is wrong" and "pushing for walking" there was thread of hope that things would not change for the worse. This hope was felt by both spouses and children who hoped that their family members could return to their lives in the community and that they would not need to go permanently to a nursing home.

Hoping Things Don't Change

During the hospital stay, family members found that they had to be the voice of advocacy for the frail older adult. At no other time was the complexity of the relationship more sharply felt than at the time of hospitalization when the lives of the older adult and their family members were intricately interwoven. Simply leaving the hospital was not an easy task for frail older adults and their family members. Not only was the health of the frail older adult an issue, but also the health of the family member. A wife whose husband was becoming increasingly debilitated reflected the relationship between the older adults and family members' health and also the belief that help would be available,

> "I don't foresee us making any other change. I think there will be help. But it depends on how my health goes. But I don't foresee him doing anything but staying at home."

Although there was hope that things would not change for the worse, the reality could be different. At some point in the hospitalization, decisions about discharge had to be made. For some family members that decision was clear, the patient going back home. For other family members, the decision was less clear and involved weighing complex choices about discharge destination.

Choices

For family members, choices about discharge destination were more complicated than deciding on a place. Choices about discharge destination also involved making decisions about how to help care for the older adult. Throughout this theme, there was a common thread of the need to balance the decision in light of each individual's personal values and beliefs about how your family member should be cared for. For some, the nursing home was an option that had been discussed and agreed upon without issue. A son of an older woman described this viewpoint:

> "More or less she told would like to go to the nursing home. I thought it was a good idea…. She has no trouble going there. She worked there all her life. She is used to it."

For those who needed short term-skilled care, the hospital-based unit was a more attractive option than the nursing home. Family members identified that hospital-based skilled care allowed the older adult to keep their hospital physician, not be moved to another facility, and also stay close to the more intensive services that might be emergently needed. The attractiveness of this option was explained by this spouse,

> "Of course we prefer to go home. I want to take him home… and if he required any skilled nursing we have talked about it and prefer to go to the eighth floor and he not be moved to another facility."

For others, the nursing home was a place of last resort, to be considered when all other choices had failed. Spouses were more apt to consider home the destination of choice no matter the personal cost to the caregiver. A husband who gave care to his wife described his feeling about the nursing home:

> "She has asked two or three times to go to the nursing home. But I don't even want to taste it. I have seen my mother there. I have seen other people there and I don't like it. I don't even want to get a taste of it."

For children of older adults, the issue once again hinged on new arrangements of care versus established arrangements of care. The one child who had an established relationship with his mother living in his home described how he viewed his obligations to her, “Well, I have a responsibility of taking care of her…. I went out and bought another home so I have would have enough room to have them there with me.”

It was more common for the children to be in situations where their parent required a new care arrangement and choices had to be made about the best solution for both their parent and their immediate families. Multiple issues were taken into consideration, such as the accessibility of the child’s house for the older adult, the ability of the family to provide care, and the caregivers need to have time alone with their own family. Even when children were logically trying to work with their parent to decide what would be best, it was difficult for them to help their parent make decisions about a discharge destination. A daughter explained the thorny nature of this type of decision:

> “You obviously have to wonder if this is finally it. That she has to go to a nursing home. Of course there is the emotional; no one has ever had to go to a nursing home, on her side or my dad’s side. That is a foreign thing to us; everyone has been able to stay strong and to stay put. That is a scary thing. As far as caring for her, I think about respite care if she stays with us. If know there is someone in our community if she needs to, she could go for a couple of days if we go out of town or something. Long term, I look ahead to how we can have some respite time, time away to ourselves, which is very much needed. She knows we need that, other than just going out for an evening.”

There was another aspect to making choices and that was keeping parents together. Older adults in the previous section spoke of staying with their spouses. Family members who were spouses were inclined to keep their spouse in the home.

Children also were concerned about keeping parents together. The son of a very elderly, frail man described how he viewed his father's wishes for staying with his mother, who had dementia and was in the nursing home,

> "It has been cut and dried. We knew where he would go, to get to where my Mom was at. They have been married sixty plus years. He wants to be where she is at and if he can get into a condition that he can go back home, that would be good. But that remains to be seen."

For the majority of family members that were interviewed, the older adult was going home. The choice to return home was an option that had to be processed by families. Some of the older adults were so very ill and frail that even the most dedicated of caregivers had to carefully plan the return home.

Planning for Home

The decision to return home was the first of many decisions that involved how to leave the hospital and receive care and services at home. One spouse explained that you make up your mind that this was going to happen stating, "You make room for it." The making room for it was an active process that involved planning. Subthemes of planning for home included (a) working out the details, (b) deciding how to give care, and (c) changing how they do things.

Working out the details. For those caring for very frail people at home, working out the details was a complex process. The details included identifying what care needed to be done. Care for the older adult may have been as simple as being present in the home or as complex as establishing schedules for daily care of a dependent older adult. Care might also have been medically complex, e.g. giving intravenous antibiotics and caring for central intravenous catheters. The details included identifying who would give care, or assist in giving care, and how the day would be organized for the older adult. A spouse who was considering taking her husband home described the details required in planning care.

> "The PIC [peripherally inserted catheter] line needs medications put in it every day. We have talked about that. They told us we could come in everyday and get it. We could be here in 30 minutes. We live 13 miles out and by the time he leaves here and still needs medication the weather may be bad. We have talked about that, we didn't know how we would handle that. We plan to do it all at home if at all possible."

Deciding how to give care. Working out the details required deciding how to give care. There was a need to identify who would be available to help. For some, that required garnering multiple resources to give care. Resources took the form of a spouse, other family members, or outside resources such as agency help paid for by Medicare or privately out of pocket, or any combination of these.

For spouses who had taken on the responsibility of primary caregiver there was a need to be very organized so the older adult received what they needed, but also to ensure that they, the caregiver, did not harm themselves or wear out. A husband who cared, for his frail wife talked about his viewpoint about how to give care and take time for himself.

> "It's an attitude. You can make it really tough on yourself. If you think things are going to get really tough and you don't have a rhythm set up they are going to get tough. I have a rhythm set up. Like I told you when I first get her up I know what to do, just right down the line everyday. So when I am through I just relax."

There were other spouses who had a more difficult time garnering the resources. Wives who were taking care of larger and debilitated men had particular difficulties. Managing the physical care of someone larger than themselves was a challenge. There were not always resources available from children or younger family members to help with care. One woman in particular could not turn or move her husband, who in turn was unable to do those activities by himself. When asked what she could do for spouse, her reply was quite revealing: "It's not much after doing a little cooking and clearing up, that was just about it." All her children live a distance away except for one son. She explained his role in helping his parents:

> "He works out of his home and he also helps his children. He has three grandchildren here and two sons and he helps them. He helps me and does his work and his wife has had breast cancer and he helps her. I sometimes think he is overloaded. I really do…. When I call him he says everything is all right mom, don't worry."

The lack of resources for this family made them vulnerable to problems. The patient's care was paid for privately because he did not meet the "acute medical need" requirement for Medicare Home Care eligibility. His wife developed other plans for care that included privately paying for care through a service and relying on volunteers.

The majority of children and spouses alike who were giving care had solid plans in place and were not as vulnerable as the couple described in the previous paragraph. There was recognition that things at home could change if decisions about how they gave care did not work out as planned. Even the most confident caregivers felt the stress of the situation. The return home for frail older adults and their families often resulted in change in lifestyle.

Changing how we do things. The theme of "Changing how we do things" involved many facets, from changing the physical structure of a home to deciding how to live on a day-to-day basis while caring for someone else. The simpler of these was to change the structure of the home to increase accessibility to rooms by wheelchairs and walkers. There were older adults who stopped activities because they had become too dangerous to do. One man illustrated this point well:

> "We are just normal ordinary people. We have the same concerns others have. I don't want her to fall. We started out the door one day at our apartment and there are not steps because it is handicapped accessible and she stumbled on the threshold of the door. I tried to catch her and we both fell on the patio. I said "Oh my gosh if our neighbors saw us they will call 911." We finally wallowed around and we got up."

For caregivers of the most frail, there was a narrowing of the older adult's social world. As the older adult's health declined, they and their spouse were less able to go out and be social with other people. Activities that were once enjoyed were stopped and their world slowly contracted. For spouses this seemed to be acceptable, but for children the narrowing of their world was less acceptable and there were concerns about what would happen if the caregiving role was assumed.

The challenges faced by families as they helped their older adult relative make decisions about discharge from the hospital were significant. There was complexity to the decisions that both older adult and family members were well aware of. For some there were few decisions, but for others the decisions were broader and more life-altering. The HCTM who worked with the older adult and their family member attempted to understand their positions and given needed help and support for decisions about hospital discharge.

Heath Care Team Members

The work of HCTMs was to understand the entire picture presented to them by older adults and their families. To do this successfully they had to be aware of the needs and desires of both older adults and their families. The themes of this section are filled with the nuanced understanding of a third party to family decisions. They were often aware that there was a limit to their understanding, thus attempts were made to let competent patients and their families take the lead. The first step that was made by the HCTM was assessing the situation to understand what must be attended to as the hospital discharge for the older adult was planned.

Assessing the Situation

Assessment was elemental to the clinical practice of all health care providers regardless of discipline however, what was assessed varied by discipline. Furthermore, specific roles of disciplines vary slightly depending on the hospital setting. In particular, teaching hospitals function differently than private hospitals. The setting for this investigation was a private, community hospital.

There are three major disciplines that are involved in discharge planning and decisions about discharge destinations for older adults: physicians, outcomes coordinator who were nurses, and social workers. No physicians were interviewed for this investigation. Physicians participated in planning for discharge from the hospital, but relied on other professional in disciplines such as nursing and social work to assess and decide the specific discharge plan. Nurses assessed both the physical and psychosocial needs of patients. Outcomes coordinators who were also nurses were the HCTMs who monitored patients' physical condition on an ongoing basis, decided what patients needed to learn about their condition and treatments prior to going home, assessed functional ability, and assessed the patients' and families' ability to give needed care. As with nurses, social workers assessed the psychosocial components of the situation, but they were also responsible for making complex discharge arrangements such as setting up nursing home, home health care, medical equipment, or transportation other than by private vehicle.

HCTMs used very exact language to describe their assessment role. Outcomes coordinators who were registered nurses uniformly described their roles as assessing patients' home situation, physical abilities, support systems, and help needed. Issues such as fall risk and safety were addressed by nurses and social workers alike, but because these themes compose a significant portion of the discussion they will be addressed in a separate section. An outcomes coordinator explained her basic role:

> "My role was to assess the home situation and pay attention to her physical abilities, and what support systems she has in place to determine a discharge plan for her once she was ready to leave acute care."

The disciplines were well acquainted with one another's roles. A social worker explained the role of the outcomes coordinator that she worked closely with:

> "Judy [fictitious name] helps me determine the level of care when we are ready to go, how acute is she still? More the medical piece, what meds she will be on, was she skillable [*sic*] for a medical reason, or for physical therapy. She is the one that usually communicates with the doctor."

The role of social workers in assessing the situation was complementary to that of nurses. They too thought to about the physical condition of the patient so they could effectively plan care. For the social workers, finding out what services were still available was not an easy task. Patients had often received services from other hospitals or skilled facilities in other communities. The process of finding out how many days of skilled care were still available for use, or what services would be covered by insurance took considerable time and effort. Plans for discharge could not be made until those details had been uncovered and were fully understood by the HCTM, patient, and family member. A social worker described how he accomplished this for his patient:

> "I have to find out information. He came to us from another hospital where he has spent a lot of time…. I had to find out how long he has been at the other hospital, how many skilled days he has used in the last 5 months…. So what that means is if he goes to the nursing home…. he has 10 days of coverage and he will have to pay privately for his nursing home."

Assessing the situation also involved finding out what was currently in place at home. Finding out what was working for the older adults was an integral part of assessing the situation. A social worker described his conversation with an older adult to find out what had been working at home:

> "What he had told me when he came in was that he had a walker, he hardly walked at all and he had a motorized wheelchair. That's what he told me he usually did at home. He could get up in a motorized wheelchair. He wasn't very ambulatory, but felt like the situation had been working for him and his wife."

Not all members of the HCTM assessed the situation the same way. There were times when disagreement among the team members could create problems in the discharge plan. This was particularly true when the physician made changes without consulting the outcomes coordinator or the social worker. An outcomes coordinator explained how complex the issues could get as she described the discharge plan for a frail woman who was not able to independently walk due to a new neurological condition. She required skilled nursing care for rehabilitation.

> "The doctor had written for a skilled nursing evaluation, which we had done the day before. Apparently he called upstairs and talked to the outcomes coordinator up there and she said we don't have a bed, but we may have a bed tomorrow or the next day…. Somehow he was under the impression there wasn't going to be a bed available. How he discerned that I don't know, he wrote for her to go home."

At no point was assessing the situation more valuable and essential than when issues of safety were involved. Safety was the common denominator of the discharge discussion. If going home could not be accomplished safely there was the real possibility that other discharge destinations would have to be considered.

Safety Is a Red Flag

The HCTMs were committed to ensuring that patients could go home and remain there safely. The meaning of safety varied across HCTMs. It included not falling, being able to leave the home if there was fire, eating enough food, and drinking enough water. Subthemes that emerged were (a) safety with medications and (b) having confidence in the family caregiver.

The first major element in an assessment of safety was mobility. Other issues of safety eating or drinking enough or to get escape if there was a fire were dependent on the older adults' ability to move about their house. A social worker gave a good description of what she was thinking about when she sought to send someone home safely:

> "Can you safely get from a bed to chair? Can you get to the bathroom and back safely without falling? What is your risk of falling? What is your mental status? Are you going to leave the oven on? Can you use the phone? When you fall will you use the lifeline button? There are just all kinds of gambits of thoughts. Will you hear the home health nurse at the door? There are just all kinds of thoughts about what you can set up for people."

The physical strength and the sensory ability of the older adult to correctly respond to environmental stimuli were important to the HCTM. A nurse discussed her concerns about safety. What she identified was different than the social worker.

> "To me it [safety] means they aren't a fall risk. Depending, some are always going to be a fall risk no matter what. That they can get out of their home—if

> they can't get up by themselves to get out of there if there is a fire. Can't do the basic things, go to the bathroom, not getting decubs [pressure ulcers]. Sometimes it is not a good environment at home, but it doesn't mean they can't live there. Sometimes they have a dirty house—that may be their choice. They live in shacks—that is their choice. I can't judge that part. If their basic needs are met even if they choose, it's a patient's choice."

For the majority of HCTMs of the medical and cardiology units, issues surrounding discharge destination decisions of older adults and their families were similar. Within the discussion of safety, an important distinction emerged between the two different units. On the cardiology floor, discussions about medication safety emerged as well as discussion about patients physically being able to manage in their environment.

Medication safety. The older adults who were cardiology patients were similar in functional ability and family dynamics to the patients on the medical units. However, the outcomes coordinators on the cardiology units were much more concerned about medication safety. One explanation for the difference in concerns may be that patients with cardiovascular diseases were more vulnerable to problems associated with not managing medications correctly. Those with cardiovascular diseases were more likely to be on high risk drugs, such as Coumadin, Lasix, and Plavix, drugs that if taken incorrectly may result in worsening health problems. An outcomes coordinator on the cardiology unit described her concerns about medication compliance in her patients:

> "It also makes you concerned when they have abnormal labs or certain symptoms—are they taking their medicines correctly? Even if they don't have someone who can help with their medicines—they don't quite understand. Those folks, we have several, who have come into the hospital and they don't take their medicine correctly, even though we put a home health nurse in there to set up their meds for them. It still gets mixed up. We'll have patients who say I don't know what I take. They say if don't

> remember I just take another one. Well you know we had a patient land in the hospital dehydrated because they swore someone told her to take eight of her 40 milligram (mg) Lasix pills a day. She did and she went into renal failure."

When outcomes coordinators spoke about the problems associated with correctly taking medications, they also spoke of concerns with assessing the abilities of the family caregiver. Another outcomes coordinator explained how she was going to follow-up with a concern about the family caregiver:

> "I was going to go back and interview the patient and say are you getting your medicines. Does your son give them to you? They have no home health coming in or senior services, home health aide, bath aid, or any of those things. It concerns me a little bit, he has some memory problems [her son]."

Family caregiver competence was an important element of safety identified by HCTMs of both cardiology and medicine units. For the HCTM to have felt comfortable sending an older adult home, they must also have felt comfortable with the family caregiver.

Having confidence in the family caregiver. To the HCTMs, the family caregiver was integral to assuring a safe home situation for the older adult. The HCTMs had to have confidence in the family caregiver to feel comfortable sending a frail older adult home. Confidence included believing the family member was hardy enough to manage the physical care that was required. There was also the need to identify whether or not the family member had the intellectual, emotional, and cognitive abilities to help the older adult.

The need for the family to physically handle the job was of paramount importance to the HCTMs. If the family caregiver was very frail and the HCTMs believed that the discharge to home was putting them at risk, there was a sense of disquiet about the discharge. A care coordinator related her assessment of a hardy older man who takes care of his wife:

> "He was physically capable and he was willing to take care of her. When I talked to him about what they have at home as far as tools to take of her, it seems they have all they need."

In contrast to her assessment, another outcomes coordinator related her opinion of how a home situation could end for a dedicated wife who was caring for a very frail patient with multiple complex health care needs who was extremely debilitated:

> "I think her dedication to him is so strong, that I predict one of the kids will come by because they can't get hold of her and she is going to be dead of a stroke. He is going to be sitting in his chair watching TV."

The more confident the HCTMs was with the family, the more comfortable they were with the discharge. Even discharges that were going to require the use of technology such as IV pumps at home were consider uncomplicated as long as the caregiver was capable of understanding the work that needed to be done. A social worker described her assessment of an older adult and his wife who were preparing to go home:

> "It was recommended that he have 6 weeks of IV antibiotics at home. The first thing I did before I called the insurance company was to talk with them to see if they were interested in having their antibiotics at home. Sometimes they are really uncomfortable with the pump and being taught. SNF would be an option if they didn't like the home avenue. I was very impressed with both of them. They were very teachable and alert."

The end result of the HCTMs assessing the situation and finding out about safety was to identify what options were available and acceptable to the patient and family. In most cases, multiple paths were available and it was necessary to look at the different options and decide which would be the best fit.

Weighing the Options.

During the assessment, the HCTMs made a rudimentary decision about what options were most reasonable in the situation. The frail older adults in this investigation had several options available to them. Options were not clear cut but unfolded over time as the older adult's condition improved or declined. For each situation, options would be limited not only by the older adult's desire about where to live, but also the logistics of how to receive needed care or how to pay for needed care. Realistically, there were two tangible options available to older adults, going home or going to the nursing home for a long or short term stay. A social worker related how she viewed options for an older adult and his caregiver wife:

> " … I just want them to have all their options. They can tell me which one they are interested in. I can pursue it for them; get more detail, what it would cost them. To make an informed decision, they have a lot of options in this case. With his need for more therapy, being at the hospital skilled unit may be a better option for a while. You have to do it all or nothing. You can go to the SNF for the first week and then go home. We can win both places if we can get him moving."

This viewpoint of skilled care as a stop along the way was comfortable for the HCTMs. There was an underlying understanding among the HCTMs that they did not know what people were capable of accomplishing. The HCTMs would not tell patients directly that they could not go home. Home for the HCTMs was framed as the ultimate goal for older adults, with stops along the way at a SNF or staying with family members. As a social worker said, "People are going home when they leave the hospital unless something has happened and you know they can't."

It was generally accepted by the HCTMs that they generally agreed with the older adults, that going home was the best option for them, but there was also an understanding that for some very frail old people, going home was a fragile option. Having services in place with home health care made the option of going home more realistic for the older adult. Only services such as skilled nursing or physical, occupational, or speech therapy are paid for by Medicare; other services must be paid for privately. The HCTMs uniformly agreed that older adults and their families did not always understand what was available or how care was paid for. Home care services offered a buffer to the HCTMs—to allow others to continue to monitor a discharge that may be risky. An outcomes coordinator described the use of services in the home:

> "…You can set them up with home health and have them do a home evaluation and they can recommendations too. Especially if you are really concerned that they aren't [*sic*] going to do well at home. We let them go into the home and we have social workers too. They can work with the patient and family. There are other options if it doesn't appear to be working out."

Home care services may serve as the buffer of support for patients and families, but home health care visits are infrequent and of short duration, thus do not offer much in the way of tangible relief from caregiving. It was entirely possible that the expectations of support from home health care would not be met once the older adult was back in their own home. An outcomes coordinator explains home health care:

> "There are misperceptions about home health care, a lot of people believe they come in and they do all kinds of things for you. They may only come 3 days a week. You know that is not quite the same. A lot of people don't have the financial resources to pay for a caregiver out of pocket. Insurance pays for skilled services, but not unskilled services like cleaning the house and bathing."

There was an understanding that frail older adults clung to the option of going home even when others were uncomfortable with it. Children became uncomfortable with the home option well before their parents did. In these situations, they may have hoped that the HCTMs would pressure on the older adult to go somewhere other than home. This viewpoint was illustrated by the comments of an outcomes coordinator:

> "I would say the patients usually name home as their first and only option. I don't know—I would have to take a look at it and do some data collection. But I am sure that at least half of them are hopeful that by mom or dad being in the hospital that the health care team will convince the patient to go somewhere else. To bring up—they have brought it up and it has gone nowhere. How often I hear, I am so glad you are here, maybe you can talk some sense into them."

There were also older adults who recognized that going home was not the best option for them and they needed to consider another living arrangement. The HCTMs spoke of these patients as a rarity, as people who made their jobs easier. The decision to place older adults in a nursing home when they were not in total agreement with the decision was viewed as the most difficult situation for the HCTMs to work with. When disagreement was present, it was necessary to reconcile the differences.

Reconciling the Differences

The need to reconcile differences occurred if the older adult insisted on a discharge option that was not viewed as realistic by the HCTMs. The point of contention was always about going to a nursing home instead of going home. The HCTMs described the need to reconcile the differences by (a) establishing a "realistic view," (b) "softening the blow," and (c) ultimately, if required, "letting them fail" at home.

"Realistic view." There was a need expressed by the HCTMs to establish a "realistic view." However, there was also an understanding that the HCTMs was not always sure what the "realistic view" was. This lack of clear understanding and the inability of the HCTMs to know how well or poorly an older adult would do after discharge was interpreted as a way of maintaining hope for the older adult. In this way, HCTMs helped older adults and their families to maintain the hope that they would be able to return to their previous level of ability. This viewpoint was expressed well by a social worker:

> "I don't know what the realistic view is. I don't know if they will be able to bounce back, or if they will be able to walk again or not. I don't know if that would be a realistic view. We don't know what they are facing. Possibly only you know what you can do—sometimes we don't even know that ourselves."

Nonetheless, when faced with a situation that seemed to be unworkable, the HCTMs struggled to reconcile what they believed was a good plan for the older adult and family with what the older adult wanted to do. There were time when it was necessary to have a "convincing conversation" about going to the nursing home with the patient and family. A social worker described the process,"…usually there is someone who doesn't want to go the nursing home direction and you have to have that convincing conversation with them. The need to encourage a more realistic view was identified as being vital when the caregiver was viewed as incapable of giving care, or was endangering their health to do so. The following remark illustrated the frustration and concern that an outcomes coordinator felt about a frail older woman taking her bed bound husband home, knowing he could not receive physical therapy at home because of failure to make progress in the therapy,

> "I think her head understands it. Her heart just does not—it is hard for her to accept I think. No wait, I take that back. I really do think she understood failure to progress. I think she fails to readily grasp is that she is not capable financially of paying for everything they need at home. Nor is she able to say I can't do it anymore."

"*Softening the blow*." Physicians were viewed by the HCTMs as "softening the blow" about going to the nursing home by speaking of the need to receive rehabilitation. If older adults progressed with therapy and returned home, the best outcome had been achieved. However if they did not progress, then they would be in the nursing home where they could continue to receive care. The process of "softening the blow" had an underlying sense of manipulation that the HCTM was not cognizant of, as described by this social worker:

> "……So softening the blow is saying, I think it is, approaching it in people who go to nursing facilities. People are in nursing facilities as long as they need to be. Some people live out their lives in nursing facilities, but not all the time. Some are able to get back to a level of functioning where they can go back to their previous living situation or a lower level of care, or home or whatever, you don't necessarily know in your situation what that is going to be. Hmmm, that is softening the blow, it's not manipulation, not lying, it's not hmm. I don't think—I may learn something new here."

There were times when a more overt process than "softening the blow" occurred. When there were significant concerns about the safety of the older adult or their ability to be cared for at home, the HCTMs would work more aggressively to push the older adult toward making a decision to go the nursing home. This process was described by a social worker:

> "When the doctor and therapist, when the whole team says this is a disaster they cannot go home. We will draw in the patient, if they will not agree with us—more than likely they are the person that doesn't agree with us. The spouse we can usually get them to agree with us, then the children. If there isn't any children, then we try to get some pressure on the family side to get this person to accept what the team is saying. If we don't have that and they

> are competent, then they go home and we make the hotline [call to the State Division of Senior Services abuse and neglect hotline]."

The hotline call was seen as a way of protecting the HCTMs from liability if something happened at home. There was a sense of resignation when the HCTMs spoke of discharges they saw as potentially unsuccessful. When there were extreme concerns, the HCTMs would begin the process of establishing competence and looking at potential guardianship for the older adult. However, these were not described as routine situations faced by the HCTMs.

"*Letting them fail*." Another more commonly used strategy used by the HCTMs to reconcile the differences was to "let them fail" at home. This meant setting up the discharge and allowing the older adult to do what they wanted, even when the HCTMs did not agree with them. The HCTMs believed that if the discharge failed and the patient returned to the hospital, there was another chance to work with them to set up a plan that had a better chance of succeeding. A social worker described "letting them fail:"

> "Sometimes it has to fail. Sometimes they have to go home against the doctor, outcomes coordinator, you have given them all the information and it is still their choice. They are competent, but in your mind they are making the wrong choice. Let them fail. You now they are going to be back with a broken hip in two months or something. That's hard, that's hard as a social worker. You know something is going to happen and you have a concern for them."

Reconciling different viewpoints was challenging for HCTMs. Nonetheless, it was a daily routine. The goal of the HCTMs, was to plan a discharge that would succeed. They did not want the patient to be readmitted to the hospital because the planning did not work. From the moment the older adult was admitted, until the moment they left, there was constant assessment and reassessment that occurred about the older adults' capabilities and how much and what quality of help they had at home.

Frail Older Adults, Family Members, and HCTMs

The major themes and subthemes identified for each triad were similar in few respects (Table 31). Frail older adults and their families were more similar than HCTMs. They were most interested in the older adults returning home and keeping their current living situation intact. Spouses were particularly hopeful that things would not change and their partner would return home. Children were reluctant to consider a nursing home, but would do so when the older adult's physical care became too heavy, or they saw the nursing home as reasonable short term option for therapy. HCTMs shared the belief that returning home was the best option, but also recognized that for some, the older adult's care needs would outstrip the abilities of the older adults and their family members. The concern for matching needs to resources was a large part of the HCTMs' routine and ongoing assessment of the strengths and weaknesses present in the older adults living situations.

Older adults were very concerned about remaining independent. They recognized that to go home, they needed to remain as independent as possible. For the older adult, ensuring continued independence involved getting the help they needed, as well as recognizing and accepting the need to change how they did things in their daily life. For families however, this process was different. Families were much more concerned about the reason the older adult was hospitalized. They needed to find out what was wrong and they recognized that for the older adult to remain independent, timely treatment of problems needed to occur and physical stamina and abilities needed to be maintained. Families uniformly assumed the role of advocate for their family member.

When the decision was made that home was not an option, the discussion turned to deciding where the older adult would go to live. The HCTMs described available options for the type and intensity of care that was required. The older adults identified that there were times when they needed to listen to others and consider alternatives other than going home.

Both the older adults and HCTMs spoke of the need for safety for the older adult. The older adults wanted to be safe from harm and injury. It was very interesting that the idea of safety was not discussed by family members. Keeping the older adult safe was part of the planning process done by the family, but the term "safety" was not used by them. For the HCTMs, safety was a major element of concern. Safety was interpreted much more broadly by the HCTMs than it was by the older adult. Older adults were most concerned with safety from falls. HCTMs were concerned about physical safety, proper administration of medicines, and capabilities of the older adults and their caregivers. Older adults simply did not speak of the capability of their family members to be a caregiver, but would talk of concerns for their family members' continued good health.

There was virtually no discussion by either the patient or their family about the need to reconcile different viewpoints. However, this was a major area of discussion for the HCTMs. It was a basic element of their job to assess needs and bring forward for consideration the options available to help with care.

The older adults, their family members, and HCTMs worked together well. There was not always complete agreement between the three, but there was a willingness to work together. As identified in aim #2, the three worked together in a complimentary fashion, but not with complete congruence (Table 32). Even in the one case, in which there was clear dissention about the decisions being made, the HCTM supported the decision to return home by making sure support was available in the community for the care of the older adult. Nonetheless, there were times when the HCTMs identified subtle manipulation of the patient and their family as a way to achieve the outcome seen as reasonable by the HCTMs. There was little insight by the HCTMs that the strategies were a form of manipulation, rather they were seen as a way to reduce liability for potentially problematic discharges.

Figure 4, Example calculating discrepancy scores

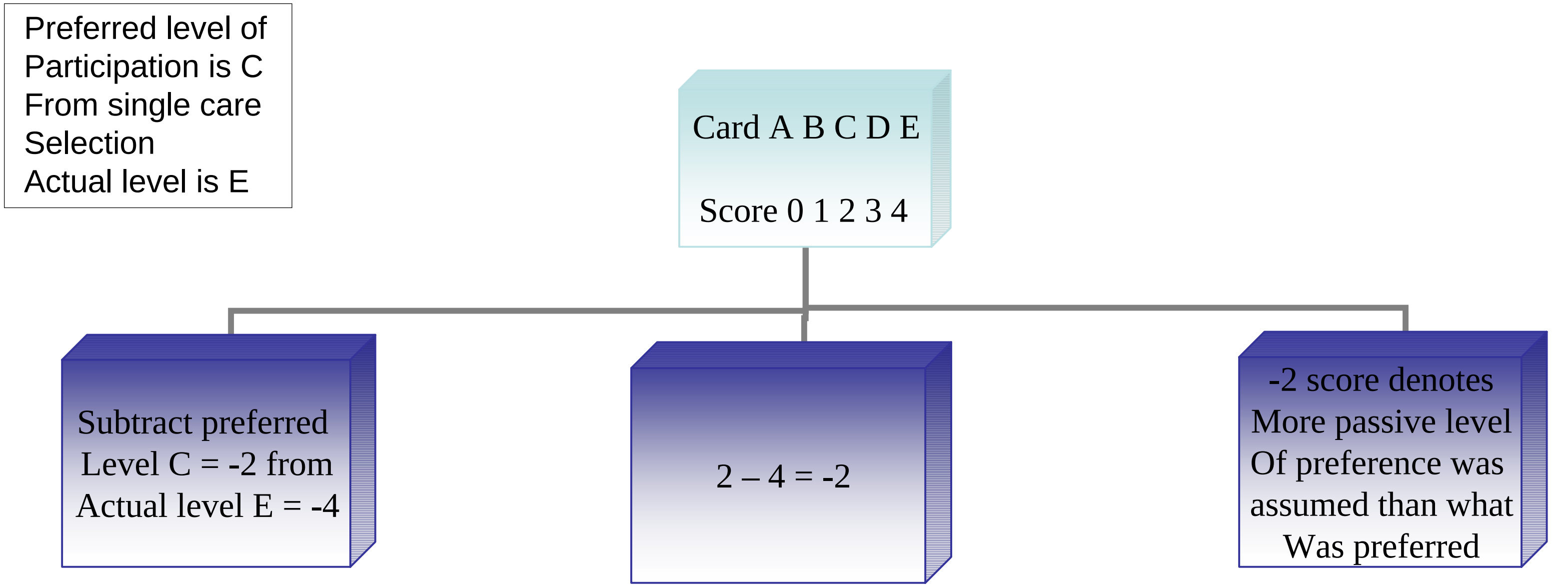
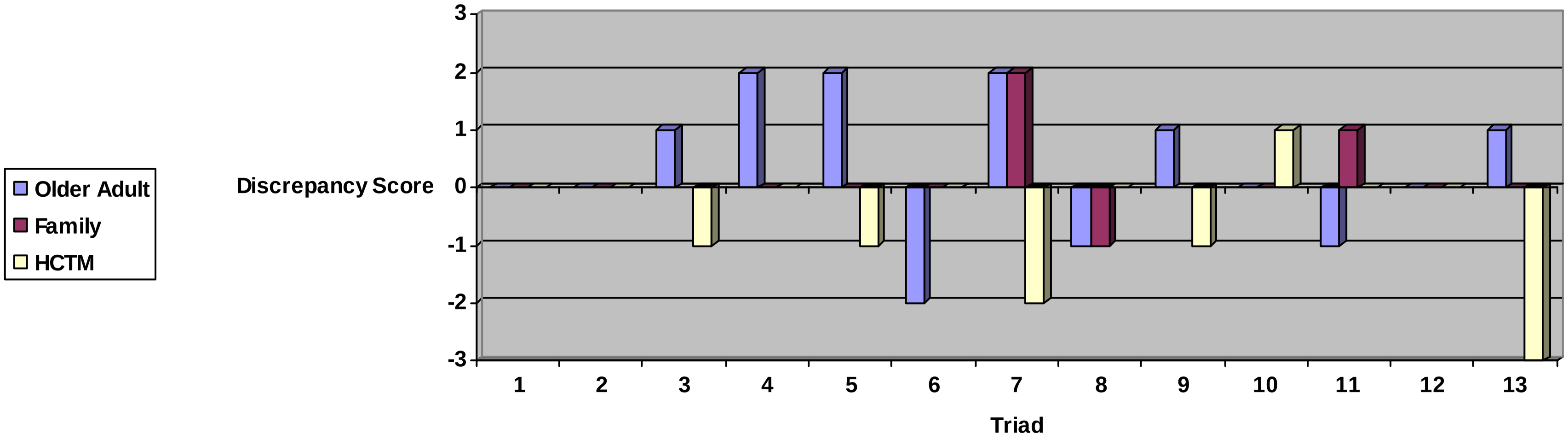


Figure 5, Discrepancy Scores for Older Adults, Family, and HCTM *



* Discrepancy scores of zero (at the zero line) indicate complete congruence between the preferred LOP and the actual LOP of the triad member. Scores greater than zero (above the zero line) indicate that the actual LOP is more active than the preferred LOP of the triad member. Scores less than zero (below the zero line) indicate that the actual LOP is more passive than the preferred LOP of the triad member.

Table 4, Demographic Characteristics of Frail Older Adults

Sample Size	n=13
Age	Mean 84 Median 84 Mode 84 Range 72-90
Gender	*Percent (number)*
Female	61.5% (8)
Male	38.5% (5)
Marital Status	
Married	61.5% (8)
Widowed	38.5% (5)
% Married by Sex	
Female	15.0% (2)
Male	38.5% (5)
Race	
Caucasian	92.3% (12)
African American	7.7% (1)
Education	
Less than High School	7.7% (1)
High School	46.2% (6)
Some College	30.8% (4)
College Degree/Post Graduate	15.3% (2)
Number of Living Children	
1 Child	15.4% (2)
2-3 Children	61.5% (8)
>3	23.1% (3)
Medical Conditions	
Acute infection	31.0% (4)
Neurological disorder	23.0% (4)
Cardiac disorder	23.0% (4)
Intractable pain	7.7% (1)
Fall related injury	7.7% (1)
Dehydration	7.7% (1)

Table 5, Frail Older Adults and Family Comparison: Daily Activities Assistance Received

Daily Activities	Older Adults Reporting Assistance	Family Members Reporting Older Adults had Assistance
	n=13	n=12
	Percent (number)	*Percent (number)*
Getting Dressed	38.5% (5)	50.0% (6)
Bathing	30.8% (4)	41.7% (5)
Toileting	38.5% (5)	33.3% (4)
Grocery Shopping	53.8% (7)	75.0% (9)
Other Shopping	53.8% (7)	75.0% (9)
Housekeeping	61.5% (8)	58.3% (7)
Yard Work	76.9% (10)	83.3% (10)
Paying Bills	53.8% (7)	66.7% (8)
Getting to Appointments	61.5% (8)	75.0% (9)

Table 6, Body Mass Index, Grip Strength, Frailty Score, & SMMSE Scores by Gender

Gender	BMI	Grip	Walk Time	Frailty Score	SMMSE
Male	24.6	31	Not walked	2	5
Male	23.3	15*	Not walked	5	6
Male	28.7	24*	Not walked	4	5
Male	37.0	33	Not walked	3	6
Male	31.0	10 *	Not walked	5	4
Female	19.6	12*	Not walked	4	6
Female	25.8	11*	Not walked	4	5
Female	22.9	16*	Not walked	4	6
Female	24.0	14*	20 seconds **	4	6
Female	20.3	13*	19 seconds **	3	5
Female	25.0	0*	Not walked	4	4
Female	18.0	8*	Not walked	3	3
Female	25.0	8*	Not walked	3	6

*Positive for low grip strength based on BMI

** Cutoff for walk time ≤ 7 seconds to walk 15 feet

To be included in study, frailty score must be ≥ 2 and SMMSE ≥ 3

Table 7, Demographic Characteristics of Family Members

Sample Size	n=12
Age	Mean 71 Median 73 Mode 46 * Range 46-88
Gender	*Percent (number)*
Female	50.0% (6)
Male	50.0% (6)
Marital Status	
Married	91.7% (11)
Widowed	8.3% (1)
Relationship to Older Adult	
Spouse	58.3% (7)
Child	41.7% (5)
Race	
Caucasian	91.7% (11)
African American	8.3% (1)
Education	
High School	41.7% (5)
Some College	33.3% (4)
College Degree/Post Graduate	25.0% (3)

* Multiple modes existed. Smallest value is shown.

Table 8, Demographic Characteristics of HCTMs

Sample Size	n=7
Age	Mean 47 Median 47 Mode 47 Range 40-57
Gender	*Percent (number)*
Female	76.0% (6)
Male	14.0% (1)
Caucasian	100% (7)
Position Held	
Outcomes Coordinator RN	71.4% (5)
Social Worker	28.6% (2)
Number of Positions Held Last Five Years	
One	57.0% (4)
Two	14.0% (1)
Three	29.0% (2)
Number of times interviewed	
One	57.0% (4)
Two	14.0% (1)
Three	14.0% (1)
Four	14.0% (1)

Table 9, CPS Metric Card Order 1-11 Results Older Adults, Family Members, and HCTMs

Control Preferences Metric		
Metric #	*Card Order*	*Two Most Preferred Levels*
1	ABCDE	Active-Active
2	BACDE	Active-Active
3	BCADE	Active-Collaborative
4	BCDAE	Active-Collaborative
5	CBDAE	Collaborative-Active
6	CDBAE	Collaborative- Passive
7	CDBEA	Collaborative- Passive
8	CDEBA	Collaborative- Passive
9	DCEBA	Passive-Collaborative
10	DECBA	Passive-Passive
11	EDCBA	Passive-Passive

Card Orders Selected		
Older Adult	Family	HCTM
6	8	9
*	6	9
-	*	-
*	-	9
2	7	10
*	*	11
*	1	8
*	*	8
*	2	9
6	-	10
*	5	11
9	3	9
*	*	*
4	9	2

Table 10, CPS Results 1-6 Categorical Breakdown

Older Adult	Family	HCT
4	4	5
2	4	5
-	5	-
2	-	5
1	4	6
3	3	6
3	1	4
3	5	4
4	1	5
4	-	6
*	3	6
5	2	5
3	3	*
2	5	1

Categories represent the two most preferred LOPs E.g. to have an active/active LOP any combination of cards A or B must have been chosen.

* Not able to categorize

Key to table 9

CPS Categories	*Two Most Preferred Levels*
1	Active-Active
2	Active-Collaborative
3	Collaborative-Active
4	Collaborative-passive
5	Passive-collaborative
6	Passive-passive

Table 11, Number of Participants in Three Categories of CPS Decision-Making Levels

	Older Adult	Family	HCT
Active	4	3	1
Collaborative	7	6	2
Passive	1	3	9
Not a valid response *	Active/passive		Passive/active

* There were not categories for these two responses. Active and passive are opposite ends of the decision-making continuum and cannot be categorized together.

Table 12, Comparison of First Two Preferred Levels of Participation for Card Orders Not on Original CPS 1-11 Metric

Participant	Card Order	Closest Metric	Same First Two Categories
Older Adult	ADBCE	ABCDE	No
Older Adult	BCDEA	BCDAE	Yes
Older Adult	BCDEA	BCDAE	Yes
Older Adult	CABDE	CBDAE	Yes *
Older Adult	CBADE	CBDAE	Yes
Older Adult	CBADE	CBDAE	Yes
Older Adult	CBDEA	CBDAE	Yes
Older Adult	CEDBA	CDEBA	Yes **
Family	ECDBA	EDCBA	No
Family	ECDBA	EDCBA	No
Family	CBADE	CBDAE	Yes
Family	CBDEA	CBDAE	Yes
HCTM	DBCEA	DCEBA	No

*A and B are both active

** E and D are both passive

Table 13, Revised CPS 1-6 Categories Comparing Family Members and HCTMs

Comparison Revised CPS Categories Family and HCTMs					
Family Members	**HCTMs**				
Frequency **Percent**	**1**	**4**	**5**	**6**	**Total**
1	0 0.00	1 10.0	1 10.0	0 0.00	2 20.00
2	0 0.00	0 0.00	1 10.0	0 0.00	1 10.00
3	0 0.00	0 0.00	0 0.00	2 20.0	2 20.00
4	0 0.00	0 0.00	2 20.0	1 10.0	3 30.00
5	1 10.0	1 10.0	0 0.00	0 0.00	2 20.00
Total	1 10.0	2 20.0	4 40.0	3 30.0	10 100.0
Frequency Missing = 4					

1=active-active, 2=active-collaborative,
3=collaborative-active, 4=collaborative-passive
5=passive-collaborative, 6=passive-passive

Table 14, Revised CPS 1-6 Categories Comparing Family Members and Older Adult

Comparison Revised CPS Categories Family Members and Older Adult						
Family Members	**Older Adult**					
Frequency **Percent**	**1**	**2**	**3**	**4**	**5**	**Total**
1	0 0.00	0 0.00	1 10.0	1 10.0	0 0.00	2 20.00
2	0 0.00	0 0.00	0 0.00	0 0.00	1 10.0	1 10.00
3	0 0.00	0 0.00	2 20.0	0 0.00	0 0.00	2 20.00
4	1 10.0	1 10.0	0 0.00	1 10.0	0 0.00	3 30.00
5	0 0.00	1 10.0	1 10.0	0 0.00	0 0.00	2 20.00
Total	1 10.0	2 20.0	4 40.0	2 20.0	1 10.0	10 100.0
Frequency Missing = 4						

1=active-active, 2=active-collaborative,
3=collaborative-active, 4=collaborative-passive
5=passive-collaborative, 6=passive-passive

Table15, Revised CPS 1-6 Categories Comparing Older Adult and HCTMs

Comparison of Revised CPS Categories Older Adult and HCTMs					
Older Adult	**HCTMs**				
Frequency **Percent**	**1**	**4**	**5**	**6**	**Total**
1	0 0.00	0 0.00	0 0.00	1 9.09	1 9.09
2	1 9.09	0 0.00	2 18.1	0 0.00	3 27.27
3	0 0.00	2 18.1	0 0.00	1 9.09	3 27.27
4	0 0.00	0 0.00	2 18.1	1 9.09	3 27.27
5	0 0.00	0 0.00	1 9.09	0 0.00	1 9.09
Total	1 9.09	2 18.1	5 45.4	3 27.2	11 100.0
Frequency Missing = 3					

1=active-active, 2=active-collaborative,
3=collaborative-active, 4=collaborative-passive
5=passive-collaborative, 6=passive-passive

Table 16, Comparison Every Subset of Two Cards by Family Members and HCTMs

Comparison of Every Subset of Two Cards Family and HCTMs						
Family	**HCTMs**					**Total**
Frequency **Percent**	**AA**	**CP**	**PA**	**PC**	**PP**	
AA	0 0.0	1 9.09	0 0.0	1 9.09	0 0.00	2 18.18
AC	0 0.0	0 0.00	0 0.0	1 9.09	0 0.00	1 9.09
CA	0 0.0	0 0.00	1 9.0	0 0.00	2 18.1	3 27.27
CP	0 0.0	0 0.00	0 0.0	2 18.1	1 9.09	3 27.27
PC	1 9.0	1 9.09	0 0.0	0 0.00	0 0.00	2 18.18
Total	1 9.0	2 18.1	1 9.0	4 36.3	3 27.2	11 100.0
Frequency Missing = 3						

AA=active-active, CA=collaborative-active
AC=collaborative-active, CP=collaborative-passive
PC=passive-collaborative, PP=passive-passive

Table 17, Comparison Every Subset of Two Cards by Family Members and Older Adult

Comparison Every Subset of Two Cards by Family Members and Older Adult							
Family Members	**Older Adult**						**Total**
Frequency **Percent**	**AA**	**AC**	**AP**	**CA**	**CP**	**PC**	
AA	0 0.0	0 0.00	0 0.0	1 9.09	1 9.09	0 0.0	2 18.18
AC	0 0.0	0 0.00	0 0.0	0 0.00	0 0.00	1 9.0	1 9.09
CA	0 0.0	0 0.00	1 9.0	2 18.1	0 0.00	0 0.0	3 27.27
CP	1 9.0	1 9.09	0 0.0	0 0.00	1 9.09	0 0.0	3 27.27
PC	0 0.0	1 9.09	0 0.0	1 9.09	0 0.00	0 0.0	2 18.18
Total	1 9.0	2 18.1	1 9.0	4 36.3	2 18.1	1 9.0	11 100.0
Frequency Missing = 3							

AA=active-active, CA=collaborative-active
AC=collaborative-active, CP=collaborative-passive
PC=passive-collaborative, PP=passive-passive

Table 18, Comparison Every Subset of Two Cards by Older Adult and HCTMs

Comparison Every Subset of Two Cards by Older Adult and HCTMs						
Older Adult	**HCTMs**					
Frequency **Percent**	**AA**	**CP**	**PA**	**PC**	**PP**	**Total**
AA	0 0.0	0 0.00	0 0.0	0 0.00	1 7.69	1 7.69
AC	1 7.6	0 0.00	0 0.0	2 15.3	0 0.00	3 23.08
AP	0 0.0	0 0.00	0 0.0	0 0.00	1 7.69	1 7.69
CA	0 0.0	2 15.3	1 7.6	0 0.00	1 7.69	4 30.77
CP	0 0.0	0 0.00	0 0.0	2 15.3	1 7.69	3 23.08
PC	0 0.0	0 0.00	0 0.0	1 7.69	0 0.00	1 7.69
Total	1 7.6	2 15.3	1 7.6	5 38.4	4 30.7	13 100.0
Frequency Missing = 1						

AA=active-active, CA=collaborative-active
AC=collaborative-active, CP=collaborative-passive
PC=passive-collaborative, PP=passive-passive

Table 19, Individual Discrepancy Scores and Percentages of Older Adult, Family Members, and HCTMs

Congruence Scores	Older Adult n=13	Family Members n=12	HCTMs n=13 Interviews
-3*	0	0	1
-2*	2	0	1
-1*	4	1	1
More passive	46%	8%	23%
0**	3	9	7
No discrepancy	23%	75%	54%
1***	2	1	3
2***	2	1	0
3***	0	0	0
More active	31%	17%	23%

*Negative scores denoted more passive level of participation preferred than actual

**No discrepancy between actual and preferred level of participation

***Positive scores denoted a more active level of participation preferred than actual

Table 20, Comparing Preferred LOP Family Members and HCTMs

Preferred LOP * Family Members and HCTMs					
Family Member	**HCTMs**				
Frequency **Percent**	**B**	**C**	**D**	**E**	**Total**
A	0 0.00	1 9.09	0 0.00	0 0.00	1 9.09
B	0 0.00	0 0.00	2 18.1	0 0.00	2 18.18
C	0 0.00	0 0.00	4 36.3	2 18.1	6 54.55
D	1 9.09	0 0.00	0 0.00	0 0.00	1 9.09
E	0 0.00	1 9.09	0 0.00	0 0.00	1 9.09
Total	1 9.09	2 18.1	6 54.5	2 18.1	11 100.0
Frequency Missing = 3					

* Level of Participation: A = active, B = active,
C= collaborative, D= passive, E = passive

Table 21, Comparing Preferred LOP Family Members and Older Adult

Preferred LOP* Family Members and Older Adult					
Family Members	**Older Adult**				
Frequency **Percent**	**A**	**B**	**C**	**D**	**Total**
A	0 0.00	0 0.00	1 9.09	0 0.00	1 9.09
B	0 0.00	0 0.00	1 9.09	1 9.09	2 18.18
C	2 18.1	1 9.09	3 27.2	0 0.00	6 54.55
D	0 0.00	1 9.09	0 0.00	0 0.00	1 9.09
E	0 0.00	0 0.00	1 9.09	0 0.00	1 9.09
Total	2 18.1	2 18.1	6 54.5	1 9.09	11 100.0
Frequency Missing = 3					

*Level of Participation: A = active, B = active,
C= collaborative, D= passive, E = passive

Table 22, Comparing Preferred LOP Older Adult and HCTMs

Preferred LOP * Older Adult and HCTMs					
Older Adult	**HCTMs**				
Frequency **Percent**	**B**	**C**	**D**	**E**	**Total**
A	0 0.00	0 0.00	1 7.69	1 7.69	2 15.38
B	1 7.69	0 0.00	2 15.3	0 0.00	3 23.08
C	0 0.00	2 15.3	4 30.7	1 7.69	7 53.85
D	0 0.00	0 0.00	1 7.69	0 0.00	1 7.69
Total	1 7.69	2 15.3	8 61.5	2 15.3	13 100.0
Frequency Missing = 1					

* Level of Participation: A = active, B = active, C= collaborative, D= passive, E = passive

Table 23, Comparing Actual LOP Family Members and HCTMs

Actual LOP* Family and HCTMs				
Family	**HCTMs**			
Frequency **Percent**	**C**	**D**	**E**	**Total**
A	1 9.09	1 9.09	0 0.00	2 18.18
C	0 0.00	7 63.6	1 9.09	8 72.73
D	0 0.00	0 0.00	1 9.09	1 9.09
E	0 0.00	0 0.00	0 0.00	0 0.00
Total	1 9.09	8 72.7	2 18.1	11 100.0

*Level of Participation: A=active, B= active, C=collaborative, D=passive, E=passive

Table 24, Comparing Actual LOP Family and HCTMs

Actual LOP* Family and HCTMs				
Family	**HCTMs**			**Total**
Frequency **Percent**	**C**	**D**	**E**	
A	1 9.09	1 9.09	0 0.00	2 18.18
C	0 0.00	7 63.6	1 9.09	8 72.73
D	0 0.00	0 0.00	1 9.09	1 9.09
E	0 0.00	0 0.00	0 0.00	0 0.00
Total	1 9.09	8 72.7	2 18.1	11 100.0

*Level of Participation: A=active, B= active,
C=collaborative, D=passive, E=passive

Table 25, Comparing Actual LOP Older Adult and HCTMs

Actual LOP* Older Adult and HCTMs				
Older Adult	**HCTMs**			
Frequency **Percent**	**C**	**D**	**E**	**Total**
A	1 7.69	1 7.69	2 15.3	4 30.77
B	0 0.00	1 7.69	1 7.69	2 15.38
C	1 7.69	2 15.3	0 0.00	3 23.08
D	0 0.00	2 15.3	0 0.00	2 15.38
E	0 0.00	2 15.3	0 0.00	2 15.38
Total	2 15.3	8 61.5	3 23.0	13 100.00
Frequency Missing = 1				

* Level of Participation: A=active, B=active, C=collaborative, D=passive, E=passive

Table 26, Comparison Frailty Score and Preferred Level of Participation (LOP)

Comparison Frailty and Preferred LOP *					
Frailty Score *	**Preferred LOP ****				**Total**
Frequency **Percent**	**A**	**B**	**C**	**D**	
2	0 0.00	0 0.00	1 7.69	0 0.00	1 7.69
3	1 7.69	0 0.00	2 15.3	1 7.69	4 30.77
4	0 0.00	2 15.3	4 30.7	0 0.00	6 46.15
5	1 7.69	1 7.69	0 0.00	0 0.00	2 15.38
Total	2 15.3	3 23.0	7 53.8	1 7.69	13 100.00

* Higher scores indicate more frailty

** Level of Participation: A=active, B=active, C=collaborative, D=passive, E=passive

Table 27, No Discrepancy between Members Preferred and Actual Levels of Participation (LOP) for Older Adults, Family Members, HCTMs

	Score	Two LOP	Preferred LOP	Actual LOP	Family Involved in DM*	Individual Congruence	Triad Congruence	Themes of Congruence or Incongruence
Triad 1							Congruent	Worked together as a team (spouses) Supported family decision-making Strongly collaborative and passive
OA	0	CP	C	C	Yes	Congruent		
Family	0	CP	C	C	Yes	Congruent		
HCTM	0	DC	D	D	No	Congruent		
Triad 2							Incongruent	Each team member lacked knowledge of what the other was thinking about the discharge e.g. permanence of the decision Daughter had concerns about losing privacy Mother took the lead in making plans Communication among the triad lacking
OA	0	BC	B	B	No	Congruent		
Family	0	CP	C	C	No	Congruent		
HCTM	0	DC	D	D	No	Congruent		

OA= Older Adult, DM = decision-making, A=active, B=active, C=Collaborative, D=Passive, E=Passive

Table 28, Discrepancy in One of Three Members Between Preferred and Actual LOP* for Older Adult, Family, HCTM

	Score	Two LOP	Preferred LOP	Actual LOP	Family Involved in DM	Individual Congruence	Triad Congruence	Themes of Congruence or Incongruence
Triad 1							Congruent	Wanted to go home but willing to go to the nursing home for therapy Son recognized he could not take care of his father HCTM saw himself as “legs” for them, helping to make plans they had agreed upon
OA	-1	BA	B	C	No	Incongruent		
Family	0	CD	C	C	No	Congruent		
HCTM	0	DE	D	D	No	Congruent		
Triad 2							Congruent	He was dependent on his wife and let her make decisions She was very independent and hardy She involved him in decisions She did not perceive his increased health care needs as a problem for them to manage at home They did not share information with their children—just between each other
OA	+2	CA	C	A	Yes	Incongruent		
Family	0	AA	A	A	Yes	Congruent		
HCTM	0	CC	C	C	No	Congruent		
Triad 3							Incongruent	He was going home and his wife was to care for him She would consider skilled nursing facility (SNF) He talked more consistently about home She used collaborative language, he did not He was completely dependent on her for care HCTM was comfortable with home or nursing home
OA	0	AD	A	A	No	Congruent		
Family	0	CB	C	C	No	Congruent		
HCTM	+1	ED	E	D	No	Incongruent		
Triad 4							Congruent	She was extremely frail and relied on him He made decisions for the both of them but talked with her about it Strong desire to go to SNF for rehabilitation to get stronger so he could take her home She was willing to go to SNF but wanted to go home Children were there if needed
OA	-1	CB	C	D	No	Incongruent		
Family	0	CB	C	C	No	Congruent		
HCTM	0	DB	D	D	No	Congruent		

OA= Older Adult, LOP = Levels of Participation, DM= decision-making, A=active, B=active, C=Collaborative, D=Passive, E=Passive

Table 29, Discrepancy in Two of Three Members Between Preferred and Actual LOP* for Older Adults, Family Members, HCTMs

	Score	Two LOP	Preferred LOP	Actual LOP	Family Involved DM	Individual Congruence	Triad Congruence	Themes of Congruence or Incongruence
Triad 1							Congruent	Both mother and daughter agreed to plan Plan was comfortable seen as temporary The daughter did not hesitate to agree that her mother home to her home, perhaps indicating she had previously considered it Mother was willing to follow child's lead HTCMs in agreement
OA	-2	CA	C	E	No	Incongruent		
Family	0	CA	C	C	Yes	Congruent		
HCTM	+1	EA	E	D	No	Incongruent		
Triad 2							Congruent	Both mother and son were attempting to be more passive with one another indicating respectful for one another's position She was willing to follow her child's wishes HCTM in agreement
OA	-1	CE	C	D	Yes	Incongruent		
Family	-1	BA	B	C	Yes	Incongruent		
HCTM	0	DC	D	D	No	Congruent		
Triad 3							Congruent	Son had made a home for his mother No new decisions were required Some concerns about caregiver capability HCTM was assessing and working with family regarding capability concerns
OA	-1 +1	DC	D	E	Yes	Incongruent		
Family	0	BC	B	A	Yes	Incongruent		
HCTM		DC	D	D	Yes	Congruent		
Triad 4							Incongruent	His wife was unable to manage his physical care No involved family in the community Son lived in neighboring community All physical care paid for privately Home Health was available short-term Patient going home against recommendation of HCTMs
OA	1	BC	B	A	No	Incongruent		
Family	0	DC	D	D	No	Congruent		
HCTM	-3	BA	B	E	No	Incongruent		

OA= Older Adult, LOP = Levels of Participation, DM= decision-making, A=active, B=active, C=Collaborative, D=Passive, E=Passive

Table 30, Discrepancy Between All Members Preferred and Actual LOP* for Older Adults, Family Members, HCTMs

	Score	Two LOP	Preferred LOP	Actual LOP	Family Involved in DM	Individual Congruence	Triad Congruence	Themes of Congruence or Incongruence
Triad 1							Congruent	Wished to go to a nursing home closer to home Family was pleased with her decision No longer qualified to stay in the hospital
OA	-1	BC	B	C	No	Incongruent		
Family	--							
HCTM	+1	DC	D	C	No	Incongruent		
Triad 2							Congruent	Very independent No family she was willing to work with She understood the need to go to a nursing home HCTM considered her "interesting" and stood by her rights to make her own choices
OA	+1	CD	C	D	No	Incongruent		
Family	--							
HCTM	-1	DE	D	E	No	Incongruent		
Triad 3							Congruent	Long standing arrangement of care plan in place that was working well Spouses very committed to one another Patient was willing to go to a nursing home if he became ill and could not care for her HCTM had no concerns about discharge plan
OA	+2	CB	C	A	No	Incongruent		
Family	+2	EC	E	C	No	Incongruent		
HCTM	-2	CD	C	E	No	Incongruent		

* Level of Participation, OA= Older Adult, LOP = Levels of Participation, DM= decision-making, A=active, B=active, C=Collaborative, D=Passive, E=Passive

Table 31, Themes of Decisions about Hospital Discharge Destination

Older Adult		
	Theme	Subtheme
	Home	“Staying together”
	Independence	“Getting the help I need” “Changing how I do things”
	“Where I End Up”	Who decides Staying safe Listening to Others Nursing Home
Family Members		
	Finding Out What is Wrong	Advocating for them Pushing for walking
	Hoping things don’t change	
	Choices	
	Planning for home	Working out the details Deciding how to give care Changing how we do things
Health Care Team Members		
	Assessing the Situation	
	Safety is a Red Flag	Medication safety Confidence in the caregiver
	Weighing the Options	
	Reconciling the Differences	“Realistic view” “Softening the blow” “Letting them fail”

Table 32, Themes Present in Congruent and Incongruent Triads about Discharge Destination Decisions

Older Adults		
	Incongruent Sets	Congruent Sets
		Home
	Independence	
	“Where I End Up”	
Family Members		
		Finding Out What is Wrong
	Hoping things don’t change	
	Choices	
	Planning for home	
Health Care Team Members		
		Assessing the situation
	“Safety is a red flag”	
		Weighing the Options
	Reconciling the differences	

CHAPTER 5

Discussion

Decisions that occur in health care settings are dynamic and complex. In the present study, there were many issues and concerns for frail older adults and family members that related to the hospital discharge destination decision. These issues included concerns about the care environment, caregiver availability, payment, and safety. Furthermore, hospitalized frail older adults found that the decision to go home from the hospital was complicated by the values, beliefs, and concerns of family members and HCTMs alike. For many older adults in the present study, home was not a choice they made; it was simply where anyone went after being in the hospital. However, for family members and HCTMs, home was a deliberate choice. It was not just where you went after leaving the hospital; it was a choice of destination that required careful planning to help ensure that the older adult would remain home safely and also have adequate support. Choice of discharge destination also required that frail older adults, family members, and HCTMs reach congruence about the discharge destination decision.

Individual Congruence

In the present study, participants identified how much they preferred to participate in the decision-making process. Older adults followed their preference for levels of participation in decision-making less often than did family members or HCTMs. Both patients and their family members preferred a more collaborative LOP than did HCTMs.

Degner and Russell (1988) and Degner and Sloan (1992) found in two studies about decision-making in cancer treatment, that patients preferred shared decision-making, but were more willing for their physicians than their family to make treatment decisions. In the present study, participants did not want physicians to make decisions about their discharge destination for them. However, this may be a manifestation of the different types of decisions under investigation. Degner and Russell used cancer treatment decisions. Decisions about medical treatment may be more prone to the effect of physician or advanced practitioner influence. The decision about hospital discharge destination is a decision that is more in the patients' and family members' control.

Davison et al. (2002) studied decision-making preferences of men with cancer and their partners. The study found that men had active or collaborative preferences for LOP, as did their partners. This study was unique; there were very few studies that addressed decision-making in dyads using the CPS. Once again, the findings of the present study were consistent with Davison et al. However, there were differences between the studies. Eighty couples participated in Davison's study. That was a much larger sample than the present study. Also, the average age of the participants was 61 years, which was a much younger population than the present study. The CPS card sort was done using computer technology. The purpose of the study was to identify information and decision preferences for men and their partner. However, no attempt was made to determine if the partners worked together to achieve decisional congruence.

The idea that patients and their family members wish to share decision-making for medical care has been well-established (O’Connor et al., 2003; Roberto, 1999). What was not so widely discussed was the process used to achieve decisional congruence. In the present study, a failure of participants to achieve individual congruence in decision-making did not translate to overall incongruence with the hospital discharge destination decision. Decision-making as a triad was a complex process. Each person involved in the decision needed to recognize and communicate their individual concerns to the other members of the triad. HCTMs preferred to be and actually were more passive than both patients and family members. Unless the HCTM had concerns about the discharge, they stayed in the background, giving information and support to the older adults and family members about agencies and services availability.

Triad Congruence or Incongruence

In the present study, it was difficult to understand what congruence or incongruence as a triad actually meant. There was no prior research in decision-making using triads against which to compare the pertinent findings. Davision, Degner, and Morgan (1995) found that men making decisions about prostate cancer depended on their wives to request information from the physician and assist with decision-making. However, these women were not participants in the study and it was not possible to identify how much they were involved in decision-making with their partners. Hack, Degner, Watson, and Sinha (2004) suggested that patients and family members together be included in research about end-of-life decision-making using the

CPS scale. There was a lack of decision-making research that was done in the health care setting using dyads or triads, much less larger more expansive family groups.

Triad congruence. In the present study, those triads with complete congruence between all members had some similarities. They were willing to work together to solve the often complex care issues that discharge to home for frail older adults presented to family members. They also worked well as a family, were able to talk about the challenges they faced, and looked for solutions. Similarly, they were aware that there would be changes in the discharge plan before discharge. These groups communicated well together while the older adults were still hospitalized. Solutions were proposed and if those did not work well, new solutions were proposed until a fit was found. They also recognized that what was decided in the hospital might not work at home. Most importantly, they were well aware of the potential challenges they faced, but had enough support from family or organizations to face those challenges.

This idea of openness in communication and building a relationship with both patients and families was found by Gaugler and Ewen, (2005). They reported that greater quality in the relationships between residents and staff in a nursing home resulted in more positive perceptions of family involvement by staff and also resulted in improved family communication. Hauser et al. (2006) used a national sample to study concordance and nonconcordance about physical symptoms, communication with physicians, caregiver needs, and future fears in terminally ill patients. They found that patients and their family members were more concerned about issues that affected the other person than they were about issues that affected themselves.

Similar to Hauser et al., the present study also found that triads that were in congruence with one another were able to work through the issues and problems in the planned discharge.

Triad incongruence. Those triads that were incongruent were different from the congruent triads in one major respect: at least one of the members of the incongruent triad had concerns about the discharge plan not working, but did not share those concerns with the others in the triad. By far the most prominent issue was lack of communication between the members of the triad, which led to a general lack of knowledge between individual members about what others were thinking. The concerns generally centered on the practical issues of giving care so that the older adults could remain in their home. The concerns about caregiving at home found in the present study were also found in the caregiving literature and included such issues as the need for practical assistance with daily activities (Ladkita & Ladkita, 2001) and the development of caregiver strain related to challenging care routines at home (Allen & Ciambrone, 2003).

In two of the incongruent triads in the present study, the member that voiced the most concern about the discharge was not the one that had an individually incongruent score. The individuals with incongruent scores were both family members, one a spouse and the second a daughter. In both of these triads, the care for the older adult was going to be prolonged or possibly permanent. These findings were consistent with the study identified earlier by Proctor et al. (2001) concluding that lack of preparation, emotionally and practically, to assume the caregiving role was the major reason hospital discharges were not successful.

Congruence

Congruence for the present study was operationally defined as agreement between preferred and actual LOPs. This was the same definition used by Hack et al. (2004) in their study of the benefits of participating in medical decision-making. It was intriguing that individual congruence did not impact congruence of the triad. Congruence in preferred LOP has been identified has an important element to satisfaction with decision-making about treatment between patients and physicians (Ford, Schofiled, & Hope, 2003; Jhang, Martin, Golin, DiMatto, 2005; Murray, Pollack, White, & Lo, 2006). Congruence in the present study was much more involved than meeting preferred LOP. Congruence was achieved when: (a) there was ongoing communication between older adults, family members, and HCTMs, (b) there was not a perceived safety issue for the older adult, (c) post hospital care was not medically complex for families to manage, and (d) the older adults were returning to an environment of their choice.

Home Not a Choice

The older adults in the study had one prevailing goal while hospitalized and that was to go home. They revealed that they wanted to find out what was physically wrong with them and have the problem fixed, but ultimately their energy was placed toward getting out of the hospital. While being interviewed, they spent surprisingly little time discussing their current illness—uniformly the conversations looked ahead to leaving the hospital, to going home. This was true even for those who been hospitalized for months, and had lost the ability to walk, transfer to a chair, or go to the toilet independently. These older adults expressed the need to be treated, and to get well, but most of all they wanted to get out of the hospital and go home. Most of the older adults in the present study were planning to go into rehabilitation after they left hospital. Nonetheless, going home was their ultimate goal; however, to do that they had to get stronger. Thus, going to rehabilitation was viewed as a temporary setback, but one that was needed in order for them to achieve their goal of going home. Going to rehabilitation involved a short stay in either hospital based skilled nursing care (SNF) or a stay in a Medicare Part A bed at the nursing home. Both options were acceptable as long as they could receive rehabilitation.

Home has a specific meaning to most people. Home is not only a place, but also a way of establishing and maintaining personal identity. Kontos (1998) conceptualized home as both a place to live and a place where life had a context and "meaning that belonged only to you." Home is the place where life happens, memories are built, and where belongings and people who have meaning for the individual reside (Cookman, 1996; Mallett, 2004). In the present study, the desire to return home was very strong. For frail older adults, the hospital had no context except their illness and it was known as a place to leave as soon as possible, before they became more ill as a result of being there.

Going Someplace Other Than Home

In the present study, most of the older adults were able to successfully leave the hospital and return home. The majority perceived returning home as the ultimate goal. Nonetheless, there was a subset that was comfortable with the possibility of going to a nursing home. For them, home could be reconstructed to mean a new place where they could receive needed care and services. This new arrangement was not their first choice, but it was an acceptable choice. This finding of the nursing home as an acceptable option for a place to live was also identified by Leith (2006). In Leith’s phenomenological study, older women who made the choice to move to a new environment to receive needed care positively perceived the need to move. Similarly, in the present study, participants who had been thinking about the possibility of moving to a nursing home were able to talk about it in positive terms.

For most of the participants, home was the destination of choice, but for some who had become weak or disabled during hospitalization, rehabilitation was the next needed step. The majority of older adults spoke of rehabilitation in matter-of-fact terms as the logical place to go after hospitalization. They were very knowledgeable about what to expect from rehabilitation, some had previous experiences in rehabilitation. Nonetheless, the finding that going to rehabilitation after hospitalization was perceived as a normative process was unexpected. There had been nothing in the literature to suggest that this was a widespread phenomenon.

The most common use of post-hospital rehabilitation has been to address specific conditions related to medical or physical trauma for which significant and measurable goals were attainable. Nonetheless, research has shown that hospitalized older adults are at risk for the deleterious effects of reduced physical functioning (Creditor, 1993; Sager et al., 1996). Frail older adults were even more at risk, particularly when placed on bedrest (Brown, 2004). However, there is new research being done about the benefits of rehabilitation for deconditioned frail older adults. A recent study by Raj, Munir, Ball, and Carr (2007) concluded that rehabilitation for deconditioning after hospitalization was beneficial to older adults.

The question remains as to whether or not very frail older adults benefit from rehabilitation after being hospitalized. There was a paucity of research to answer that question. If the goal of rehabilitation is to return the frail older adult to a previous level of physical functioning, that may not be possible, yet without rehabilitation there may be little chance of recovering any function. However, if the goal is to improve the quality of life for frail elders by optimizing physical functioning, then rehabilitation for the frail elderly may have a place (Johansson, 2003).

In the present study, the desire by older adults and by their family members to go home was a pivotal reason that rehabilitation was looked upon so favorably by both of them. Both the older adults and family members knew that for the older adult to go back to their home they needed to be physically stronger and mobile. The only chance they had of successfully regaining strength was to undergo rehabilitation. There were was a single patient for whom rehabilitation had not been beneficial in the past and would not be used again, but she was the exception.

The use of physical therapy had another meaning to the HCTMs. Older adults easily accepted the idea of going to the nursing home temporarily for physical therapy. HCTMs often encouraged the use of therapy in a SNF as a way to get the older adults and their families to agree to go to the nursing home. The HCTMs also knew that once the frail older adult was in the nursing home, if they were not able to become mobile and independent in their daily activities, they would stay permanently. However, the HCTMs also recognized that they did not know how an older adult would progress with rehabilitation; therefore, going home remained a possibility.

Not Involving the Children

Older adult participants, who did not have children present in their homes as involved caregivers or other sources of help, consistently spoke of their communication with their children in the same way. Parents only informed their children of what they, the parents, wanted them to know. The reasoning for this was not clear and the investigator was left to speculate why this was the case. Some older adults identified that they did not want to burden or worry their children. An equally plausible explanation may be that this style of communication was a long-term pattern in the family. However, there may be another equally plausible explanation. Perhaps parents did not want the children to become overly involved in their day-to-day life. Peters, Hooker, and Zvonkovic (2006) identified similar findings in their study about ambivalence in parent’s relationships with their children. They found that strong feelings of independence by the parents restricted the topics they were willing to discuss with their adult children. Blieszner and Mancini (1987) similarly found that older adults did not want to rely on their children as sources of identity or activity, thus did not keep them informed at all times. They preferred their children to have their own lives and not become overly involved in theirs.

Needless to say, understanding more about what older adults choose to tell, or choose not to tell, their adult children about their daily lives and their needs, was important to the understanding of decision-making between parents and children. In modern society, parents and children are often separated by distances. The only way for them to keep in routine contact is through telephone conversations. This may not be the best way to recognize the development of physical or cognitive problems in parents.

In the present study, the lack of communication with parents did impact triadic level congruence. The older adults were frail; however, their spouses were often less frail than they were. For those couples who had successful plans for managing the patient's care in place, the reluctance to communicate with their children was not an issue. Nevertheless, for older adults whose spouses were themselves frail, not communicating with grown children about ongoing care needs was a problem. Patients were leaving the hospital and going home unable to walk or reposition themselves easily in bed, and their spouses in some cases were not able to help them. If there was no assistance from children for the physical care of their parents, and no communication with children about the seriousness of the situation, the likelihood of grave problems after discharge may increase.

For those older adults who were widowed and lived alone, the decision not to communicate with family was potentially more serious. The majority of patients who lived alone and had children as their main support did have good communication with them about their ongoing health care needs. However, those that chose not to communicate with their children about their health care needs placed themselves in the hands of health care providers to support their decisions.

The Hospital Experience

The HCTMs constantly assessed the older adults' situations, particularly evaluating the patients' ability to be independent and safe at home with or without a caregiver. If at any time, the caregiver or caregiver network was not deemed to be adequate, or was seen as unsafe to meet the patients' needs, the nursing home would become a more favorable option. This finding supported the work of Morrow-Howell, Proctor, and Mui (1991), who also found that complications in a hospital discharge plan, such as lack of caregiver or community agency support, led to less adequate discharge plans being implemented. Similar to the present study, social workers viewed nursing home placements of older adults more favorably when the discharge to home was viewed as problematic. In the present study, social workers and nurses were more likely to view permanent placement in a nursing home as the worst option for all but the most debilitated patients. Overall, they would diligently work with patients and families to plan for the services that were needed in the home.

In the present study, for frail older adults returning home, excellent discharge planning by HCTMs was an absolute necessity. Discharge from the hospital was an iterative process that was constantly changing up to the moment of discharge, thus making a smooth discharge from the hospital, in the present study, a rarity. The complications associated with poor discharge planning were well documented in the literature. Brown (1995) and Morrow-Howell et al. (1991) found that most discharge instructions were given to patients who were still very ill and unable to understand or recall the information. After patients went home from the hospital, their biggest challenge was to overcome unanticipated, therefore, potentially unmet needs that often plagued them. The issue of patients having unmet needs at the time of discharge from the hospital was commonly found in the literature. This topic has been the major impetus behind the plethora of research by nursing and social scientists in the area of discharge planning (Bowles, Foust, & Naylor, 2003; Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Mamon, 1992; Naylor et al., 2004; Oktay, 1992).

A focus of the discharge planning research was to find interventions that improved discharge outcomes in order to reduce the enormous costs associated with readmission. Naylor et al. (2004) found that when CHF patients' whose ongoing care needs were not adequately met in the community required readmission to hospital, costs were 37.6% higher over a period of a 12-month period. The Office of the Inspector General (OIG) reported between 1996 and 1997, 34,500 discharged patients were readmitted on the same day with patients costs for the readmissions exceeding $226 million dollars.

The present study did not use a longitudinal design, but there were two participants who were readmitted shortly after being discharged due to problems at home. Maracantonio et al. (1999) identified that patients were most often readmitted to the hospital for new medical problems, a relapse, a complication of treatment, an adverse drug reaction, or a problem with a caregiver, or extended care facility. Proctor, Wilcockson, Pearson, and Allgar (2001) also found that caregivers were often unprepared or simply unable to assume the caregiving role that the health care providers had envisioned, leading to an unsuccessful discharge. They also questioned what was meant by unsuccessful discharge. The investigator was told about the readmissions when the daily recruitment visit was made. These patients were readmitted for several reasons. One woman was readmitted because she had a medical need that was not fully met prior to discharge. Another older adult, in the present study was readmitted because the caregivers at home were unable meet the demands of the caregiver role.

Safety is a Red Flag

Home for HCTMs had a much different meaning than it did for patients and family members. For HCTMs, the patients' home was a place that had to be safe. Safety was a more important concern than the emotional attachment the patient had for their home. For the HCTMs, safety meant physical safety, but in a very practical way that included such things as living in their home without getting hurt, being able to be mobile without falling, getting food and water, having adequate and competent help, and taking medicines in an appropriate manner.

In the nursing literature, these elements were often subsumed under the umbrella of discharge planning. Adequate planning for discharge, as described by Bowles et al. (2003), included numerous elements that must be assessed by nurses and social workers. These elements included family and social issues, medication and treatment issues, and the impact of chronic health conditions on daily life and functioning. The idea of safety also had implications for HCTMs. Opie (1998) recognized the word "safety" was a term used by the HCTM to wield power. By simply bringing safety into the mix of issues that must be addressed at the time of hospital discharge, the axis of power could move toward a more drastic approach that was less harmonious with what the patient desired.

In the present study, the power that was present in the professional roles was an undeniable force that had the capability of pushing older patients and their families toward moving permanently to a nursing home, even when that option had not previously been fully considered. The literature supports that health care professionals have enormous power over patients (Opie, 1998) and also cling to a dominance model of power (Paterson, Russell, & Throne, 2001). Johnson, Schwiebert, and Rosenmann (1994) and Johnson, Radina, and Popejoy, found that powerful others, such as physicians or family members, made the decisions for the older adult about moving to a nursing home. McCullough, Wilson, Rhymes, and Teasdale (1995) discussed the implication of power as a competing reality for patients. They found that decisions made by patients to decide whether or not to live safely at home were the subject of debate by HCTMs.

In the present study, the HCTMs sent people home to environments they did not see as safe, but would only do so at the patient’s insistence. Before allowing them to go home, HCTMs would try to convince the patients and their family that a nursing home was indicated. If the “convincing conversation” was not successful; a plan for alternative services such as home health would be set up and the patient sent home. Patients who were not considered safe at home also were reported to the Elder Abuse and Neglect Hotline at the Department of Health and Senior Services, Division of Senior Services (DSS). However, patients were not informed that they were going to be “hotlined” when they left the hospital.

The practice of “hotlining” a competent patient because the HCTM did not agree with their wish to go home, yet not informing them they were going to “hotlined,” created an ethical dilemma. The actions by the HCTMs on the surface may appear beneficent. However, beneficence must be interpreted within the patient’s personal values and belief structure and cannot be interpreted separate from them.

Therefore, a competent patient who desires to go home to potentially unsafe circumstances has the right to do so as an autonomous human being.

This concern for patient safety led the health care team down a path of convincing the older adults that they needed to have a “realistic view” of their circumstances. A “realistic view” was not necessarily the older adults’ view of their circumstance. The process of helping patients find the “realistic view” involved following a well defined pattern of activity that had an underlying purpose of manipulation. The pattern was for the doctor to approach the patient and family first, to discuss moving temporarily to the nursing home for therapy. After the doctor’s discussion, nurses and social workers had similar discussions with the patient that supported the doctor’s recommendations. HCTMs did not perceive as manipulative or harmful the actions that they took to change the minds of older adults and family members about the nursing home.

The HCTMs were not malevolent; they believed they were doing the right thing for the patient. In this situation, the right thing has to be carefully and thoughtfully constructed taking into account the patient’s right to autonomy, the HCTMs concern for their welfare, and the need to avoid paternalistic actions. The first ethical principle that must be considered is respect for autonomy. Beauchamp, & Childress (1994) identified three components of an autonomous act: (a) intentionality, (b) understanding of the situation, and (c) without controlling influences. Beauchamp and Childress also identified that children and older adults exhibit varying degrees of understanding and independence, thus they have varying degrees of autonomous action. In the present study, HCTMs found the need to have "convincing conversations" with competent patients and to "soften the blow." The goal of the conversation was to change the older adult's mind about going home. These older adults were capable of reasoning but had made a choice that was uncomfortable for the HCTMs.

The next ethical principle that impacted the decision is beneficence. According to Beauchamp and Childress, "beneficence establishes an obligation to help others further their important and legitimate decisions" (p. 166). The rules of beneficence according to Beauchamp and Childress are (a) protect and defend the rights of others, (b) prevent harm from occurring to others, (c) remove conditions that may harm others, (d) help persons with disabilities, and (e) rescue persons in danger. Beauchamp and Childress claimed that beneficence provides the primary goal and rationale of health care, and respect for autonomy sets the moral limits on the professionals' actions. They also identified that acts of beneficence are not obligatory.

The act of calling the hotline to report a competent patient, without their knowledge, is ethically questionable. At the point that autonomy and beneficence collide is paternalism. According to Beauchamp and Childress "paternalism involves some form of interference with or refusal to conform to another person's preferences regarding his or her own good" (p, 178). They further identified that acts of paternalism involve deception, lying, manipulation of information, or nondisclosure of information and restriction of autonomous choice.

The HCTMs considered the hotline call to be a beneficent act. However, according to ethical principles they may not have been obligated to act. They were restricting the older adult's autonomous choice, but were doing so for what they considered a benevolent reason. The calls made to the hotline did fall within the reporting requirements of state law for abuse and neglect, which includes self-neglect (Department of Health and Senior Services, 2007). The act of making a hotline call without informing the patient was not ethical. Wieland (2002) in a review about abuse of older persons identified that abuse included self neglect. Health care professionals, including nurses and social workers, are mandated reporters of suspected abuse, but reporting without the person's knowledge is a violation of the principle of autonomy and creates an ethical dilemma for the reporter.

The HCTMs also perceived that they did not have any other recourse but to "hotline," because of concerns for liability. The HCTMs' emphasized this idea by the repeated statement "document, document, document," meaning that every decision was clearly documented to protect the hospital from future litigation should an older adult have a future catastrophic event at home because they were unsafe. Nonetheless, liability may have been a subliminal way for HCTMs to justify their actions, because they were not entirely morally or ethically comfortable with the process, but felt that they had no good alternatives.

Equally troubling as the hotline call, and perhaps more of an issue for patient safety, was sending a patient home knowing that the discharge plan would fail. Forster, Muff, Pearson, Gandhi, and Bates (2003) identified in a study about adverse outcomes after hospitalization that 1 in 5 patients experienced an adverse outcome requiring readmission, emergency room (ER) visits, extra lab work, or extra visits to the doctor. Bowles, Naylor, and Foust (2002) in a study about home care referrals after hospital admission found that clinicians failed to refer 26% of patients who would have benefited from home care. The importance of developing realistic discharge plans that incorporate patients' strengths and weaknesses, and that is acceptable, workable, and sustainable to them cannot be overemphasized.

For a careplan to be workable, realistic, and sustainable frail older adults need help at home. In the present study, how much help the older adults had at home varied. There were times when there were competing interests between the older adults and their family members. Arras (1995) contended that one of the main ethical challenges in long-term-care is to learn how to strike a balance between competing issues. For frail older adults going home, the balance that is struck is between their right to autonomy and live as they choose, and the family members' rights to be autonomous and not give physical care to parents. Part of the role of nurses and social workers is to work through issues where there is competition between these rights and find a way implement a realistic plan of care that has a chance of succeeding.

In the present study, patients were sent home from the hospital at their insistence with the HCTMs' knowledge that the discharge plan would fail and the patient would be readmitted. The HCTMs identified that they would have another chance to discharge them again. This approach to discharge planning had serious negative implications for the frail older adults. Each time an older adult is admitted to the hospital the likelihood of serious problems developing increases. Creditor (1993) in a classic review of the affects of hospitalization on older adults found that hospitalization led to acute confusion, falls, urinary incontinence, reduced muscle strength, and weight loss. Prolonged bedrest has been implicated as the main reason that older adults suffer functional loss after hospitalization. Sager et al. (1996) reported that 32% of patients in their study declined in ADL function and 40% declined in IADL function during hospitalization.

In the present study, HCTMs members discussed the importance of helping patients find a realistic view. Almost in the same breath, they addressed not knowing what patients were capable of achieving once they left the hospital. They believed there had to be room for patients to succeed at home, yet were uncomfortable sending them home. They understood the need to make realistic discharge plans, yet felt obligated to put in a safety net by making a hotline call. In the present study, patients were optimistic that they would do well at home even when HCTMs were not optimistic. Other investigators have also identified this. Becker and Kaufman (1995) examined illness trajectories of stroke patients from the physicians and patients' viewpoint and found that unlike physicians, patients believed their illness trajectory was open to manipulation and improvement if they worked hard enough. In her ethnography Kaufman (2005) discovered the contradictions that defined the modern hospital; autonomous decision-making was highly valued, and yet that same autonomy was constantly ignored or restrained by hospital rules, reimbursement policies, and standards of care. The contradictions imbedded in modern health care make it essential that ethics committees be involved early when there are competing viewpoints to sort through the difficult choices that must be made.

Advocacy Role

Families of frail older adults were focused on finding out what was wrong and fixing the problem. As with the older adult, they knew that prolonged hospitalization led to more problems. The older adults in the present study were frail and ill and family members recognized the need to advocate for them. The most prevailing need of the older adult that made advocacy necessary was to retain or regain their ability to walk, which several had lost due to prolonged hospitalization. Family members actively pushed to keep the older adult walking or to get physical therapy involved. The families' concerns that their loved ones were not receiving basic nursing care were justified and families kept a close watch to make sure basic nursing activities were done. Kalisch (2006), in a series of focus groups with nurses about missed work, found that nurses have had to give up basic nursing activities due to constraints on their time and competing priorities of duties in the hospital. The activities no longer routinely done for patients included ambulation, turning in bed, or feeding patients in a timely manner. In the present study, families of hospitalized patients had to be constantly vigilant to make sure that frail older adults were walked. Several of the participants had been hospitalized in multiple hospitals over a period of months and were kept on bedrest for so long they had lost the ability to walk.

The second issue necessitating advocacy for the older adults in the present study was seeking adequate pain control. Several family members had to strongly insist that something be done for improved pain control in the older adults. This was consistent with research findings that reported that pain in older adults was consistently both under-recognized and under-treated by HCTMs (Chodosh, et al., 2004; Tait & Chibnall, 2002). Family members also stepped in and helped support the patient when the patient could not or would not speak for themselves. This finding parallels the findings of researchers working in end-of-life research who have consistently found that family members often made the difference in patients receiving the care and services needed for their medical conditions, and they also served as their voice and their advocate when they could no longer speak for themselves (Meeker, 2004; Steinheuser, Clipp, McNeilly, McIntyre, &Tulsky, 2000; Tolle, Tilden, Rosenfeld, & Hickman, 2000).

Family members in the present study understood that they needed to be advocates for older adults and they willingly assumed that role. When needed care was not consistently given, they would demand that it be done. Nonetheless, some family members were more available than others, and when the older adults managed their own issues, they were often able to effectively advocate for themselves. However, this was difficult for them as most of them were quite ill.

Family members advocated for older adults when there were failures in the health care system to address their perceived needs, such as need for better pain control, and assistance with walking. This was consistent with the literature about advocacy that was focused on healthcare professionals. In a concept analysis of advocacy, Baldwin (2003) identified that nurses were only patient advocates when patients were vulnerable, likewise, family did not need to advocate for the patient unless they were unable to advocate for themselves.

Family Viewpoint of Home as the Option

There were instances when the older adult’s spouse decided that home at any cost was the goal, irrespective of their own health. There was the looming concern threaded throughout conversations with spouses that eventually there would be a time when they could not be home together. Often, concerns about giving physical care and complex treatments weighed heavily in the discussions with the family about going home. Home was no longer an option in the minds of family members when the older adults could no longer take care of themselves.

This concern about not being able to return to home was well founded; Mahoney, Eisner, Havighurst, Gray, and Palta (2000) found that older adults who were dependent in one ADL at discharge were less likely to improve at home and more likely to move to a nursing home one month after discharge. This was particularly true if there was a highly involved caregiver at home. Those without highly involved caregivers were not as likely to go to the nursing home, thus leading to speculation by the investigators that problems with care at home were not identified when a caregiver was not highly involved. In the present study, highly involved caregivers were knowledgeable of and committed to giving the care required by the older adult. They were also aware of what needed to be done to organize the home environment so that care could be given. It was impossible to compare ADL findings between the present study and Mahoney et al., because ADL scores were not obtained in this investigation. However, the majority of older adults in the present study could only walk with assistance. It was likely they had impairment in ADL function in some way at the time of hospital discharge given that it would be unlikely that ADL function would improve while they were hospitalized.

Deciding when the older adults could no longer live at home was individualized for each patient and family situation. Some family members identified the risk to their own health that caregiving presented. Burton, Zdaniuk, Schultz, Jackson, and Hirsch (2003) found in their study about spousal caregiving, that caring for a spouse with ADL impairment resulted in the decline of physical and mental health of the caregiver. In the present study, spouses were more likely to desire home for the patient at any cost. This included sacrificing their own health for their spouse. This willingness to sacrifice everything for a parent was not found with the children of the older adults.

Caron and Bowers (2003) found that caregiving was interrelational. Caregivers often gave care to preserve the care-recipients sense of self and to maintain important elements of their relationship. In the present study, frail patients and their spouses worked together as a team to stay in their home each supporting the other in some way, thus allowing their reciprocal relationship with one another to continue.

Nonetheless, there were also spouses who recognized their limitations and would encourage the older adult to come home eventually, but would set restrictions about when they could come home. These limits involved assuring that their spouse had a basic degree of functioning, e.g. walking, being able to toilet with minimal help, and eating without assistance. Also, if the patient had complex medical therapies to manage at home, a skilled nursing facility was considered more strongly by the spouse. The findings from the present study were consistent with Lundh, Sandberg, and Nolan’s (2000) finding that it was not the acute health care crisis that precipitated an admission to a nursing home, but the challenges of day-to-day care that exhausted the caregiver, because they were physically unable to continue to do the work required. Baker (2005) also found that physical function explained 29.5% of the variance in a model explaining independence in community-dwelling elders. The need to be independent in physical function was essential to living at home, but the stress on caregivers was much more profound when family members were caring for a highly debilitated family member.

Children, in the present study, had to consider the meaning of bringing a parent into their home. If the parent had not previously lived with the child, or the plan had not been set in place earlier than this current hospitalization, the decision was much more difficult. Children who were considering bringing a parent into their home for the first time needed to adjust to the idea and to decide that this was what they really wanted to do. The idea of the parent coming home with them elicited an emotional and practical struggle about what must be given up or changed in order to bring their parent into their home. Similar findings on these struggles can be found in the work of Proctor, Morrow-Howell, and Kaplan (1996) and Proctor, Wilcockson, Pearson, and Allgar (2001). Both of these studies addressed the challenges facing new caregivers, including children, who had to reorganize their lives to care for a frail parent. The result of that struggle may be the overestimation by the caregiver of what could and could not be done for the parent.

Overall, women have been found to assume the majority of caregiving, possibly because they may have stronger filial norms than do men (Gans & Silverstein, 2006; Hauser et al., 2006). In the present study, sons and male spouses were as involved in caregiving as women. Both sons and daughters of the older adult participants had or were considering having a parent live in their home. The present study did not have an ethnically diverse sample and could not address the ethnic differences present in caregiving. The single African American spousal pair in the present study chose to go home against the advice of the HCTMs. Navie-Waliser et al. (2001) identified that African Americans and Hispanics were less likely to choose to move to a nursing home or relinquish the care of a family member. Feld, Dunkle, and Schroepfer (2004) in their study of informal care networks of African Americans, Mexican Americans, and Caucasians found that African Americans were far less likely than Mexican Americans or Caucasians to rely solely on spousal support at home.

Strengths of the Study

The participants in the present study, were still hospitalized, thus were able to prospectively consider issues pertinent to the discharge destination decision and did not have to recall experiences. The investigator often met with the patient and their family member together to ask them if they were interested in enrollment. This offered the investigator an opportunity to see interactions between the older adults and their family members, which helped the investigator, establish data trustworthiness identified (Kincheloe, & McLaren, 1998, p. 288) as credibility and anticipatory accommodation.

Credibility is the portrayal of the constructed reality and the truth, value, or believability of the research findings. By interviewing frail older adults, their family members, and HCTMs in the hospital as the decision about where to go was being made, the investigator was more easily able to determine, through observations and participation, that the data were true, valuable, believable, and thus credible. The second element of data trustworthiness was anticipatory accommodation, which occurred as the investigator and her advisor routinely met and together examined data transcripts, discussed emerging themes, and emerging analysis. Ultimately, the data were compared in such a way that meaningful comparisons were made between the similarities and differences in the experiences so that a plausible and understandable view of the experience was derived.

The present study was also able to effectively identify frail older adults. The frailty phenotype measure worked well in the hospital setting. This is a new contribution to the literature. The older adults who participated in the present study were very frail, as evidence by an average score of 3.6 on the frailty phenotype measure. They were also quite elderly; the average age was 84 years.

Nonetheless, the Frailty Phenotype was not a perfect fit for the hospital setting. The majority of older adults were so frail that they were unable to perform the walking test, but if they could not get out of bed, it is reasonable to assume they could not perform a timed walk test. Both the depression questions and the activity questions were based on the last activity at home, this was done to avoid all patients being positive for those two indicators. Being in the hospital certainly may have introduced hospital based frailty due to inactivity and physical illness. The overall scores for the Frailty Phenotype were 3.7, with a median score of 4. The majority of older adults in this study were roughly twice as frail as what would have been required for inclusion in the study based on the lowest cutoff score of 2.

The older adults came from a variety of living situations including living at home with spouse, living alone, and living with their children. There were a variety of discharge destinations that were considered by participants including, home, nursing home, senior apartments without services, hospital SNFs, and children’s homes.

Many of the older adults were married, but some also lived with children, or alone with no family. There were sons, as well as daughters who participated in the study. The variety increased the ability of the findings to be generalized to older adults and their family members who come from a variety of living situations.

Limitations

There was some danger that the interview process for the present study influenced the discharge destination decision. The investigator was in daily contact with the HCTMs and no problems with last minute changes in the discharge plan related to participation in the study came to the investigator's attention. It is important to remember that decisions related to hospital discharge were fluid and were reconstructed daily based on the patient's condition, availability of family caregiver, the need for hospital beds, and availability of a discharge location for the patient.

It was highly likely that there were ongoing conversations between the patient, multiple family members, and multiple HCTMs about the details of the discharge that occurred in parallel to the study. Every attempt was made to complete the interviews with the triads very quickly so that the patient's condition would not change between their interviews and the completion of the triad's interviews. However, the investigator cannot rule out the possibility that the interview changed the final decision about discharge because decisions are often made in context. Any discussion about a decision may have influenced the final choice that was made. The interview about the discharge destination decision may have caused the participants to consider problems or concerns they may had not previously thought about.

Family members who were not interviewed may not have shared the same viewpoints as those interviewed. It was beyond the feasibility of the present study to have identified all possible participants and to have elicited their viewpoints.

It was a difficult task to find patients willing to participate who were frail, older, cognitively intact, did not come from a nursing home, with involved families. There were periods of time when hospital admissions in the target age range were either all from nursing homes, or had delirium, or dementia, thus making them ineligible for the study.

The process of interviewing frail, ill, older adults in their hospital beds may have influenced the quality of the older adults' interview data. The hospital rooms were semi-private, very noisy, almost chaotic. Interviews with older adults were interrupted numerous times so that the older adult could have needed procedures, treatments, tests, or personal hygiene done. Attempts were made to schedule interviews at different times so that the participants would not feel stressed about the interruptions. The investigator found that the level of chaos was no different during evening or weekends than during the day. The constant interruptions made it very difficult to keep conversation flowing well. The noise level of the rooms made it particularly difficult to interview older adults who had impaired hearing. However, the older adults were simply too ill or too debilitated to go to another place to talk. The interviews with older adults were often of shorter duration and had less meaningful content that those of family members and HCTMs. Family members and HCTMs were interviewed in a place other than the patient's room, which allowed for a quieter and less chaotic interview experience for them.

The CPS cards were originally developed to be used with patients who were making oncology treatment decisions; therefore, the figure in the diagram on the cards appears to be a physician. The participants did not mention the figure, nor did it seem to confuse them or help them as they considered the cards. The participants would often read the cards aloud as they compared the cards. The figure has not been mentioned as a limitation in other studies using the instrument. Nonetheless, the actual influence of the figure on participants' card selections was not known.

When HCTMs completed the CPS instrument, they were asked to consider the patient and their family as they contemplated the card choices. It was common for the HCTMs to think out-loud while they read the cards. The investigator would hear them reminding themselves to think about the patient who was participating in the study, rather than to any overall decision-making pattern they were accustomed to using. The extent, to which HCTMs thought about other patients while completing the cards, or the social desirability of their responses, is not known.

It was very difficult to recruit patients and families who were known by hospital staff to have a troubled discharge. These were patients and families who were having conflicts with hospital staff and doctors, either about treatment or the discharge plan. The nurses and social workers were reluctant to allow another person to get involved for fear that a difficult situation would become worse. This limited the investigator's access to discharges that may have been more troubled than those of the participants. It was intended that such cases would serve as the negative exemplars for discharge destination decisions. However, in the present study, there was only one triad that was troubled and they were very different from the others. The older couple was

African American, the spouse could not perform any physical care for the patient, the patient was bedbound, they did not have highly involved family, and the HCTM was concerned about his going home without additional family help. This triad did not achieve decisional congruence as a triad. It is likely that decisional congruence for patients and family members in conflict would be different than those interviewed.

There were several important groups that were not represented in the present study. First, physicians did not participate although they have a dominant role in health care decisions of all types, including hospital discharge destinations. Second, patients with dementia were not included in the present study. Older adults with dementia may have different experiences to share about discharge destination decision-making than those without dementia. Third, ethnic groups other than Caucasians were not well represented. Fourth, specific information about socioeconomic status and medical insurance information were not collected. Medicare eligibility on the basis of age was assumed rather than known. Medicaid eligibility or dual Medicare/Medicaid eligibility was unknown. Knowledge of patients' socioeconomic status was not a variable of interest in the present study although Medicaid status influences discharge planning because Medicaid recipients are more likely to get help at home with personal care or housekeeping tasks from the DSS than are middle-class patients who may not be able to afford paying privately for services.

The enrollment target for the present study included at least one African American participant in keeping with population characteristics and this goal was accomplished. Very few African Americans came to the attention of the investigator for study recruitment although the nurses were routinely asked if there were patients other than Caucasians who met the study selection criteria. A large part of the problem with recruitment of ethnic minorities was the location of the hospital in a moderate sized Midwest community that also had an academic medical center that served a larger proportion of ethnic minorities in the region. Jha, Orav, and Epstein (2007) identified that the 90% of all elderly African Americans patients were cared for in 25% of American hospitals. Those hospitals caring for elderly African Americans were most likely to be teaching hospitals located in the southern United States.

Clinical Implications

Congruence about the hospital discharge destination decision is an achievable goal for frail older adults, family members, and HCTMs. For congruence to be achieved in the present study, there had to certain conditions in place: Communication in an open manner, and a willingness to work with other people involved in the decision. For the majority of older adults going home was simply what you did when you left the hospital. Most were aware of the problems that going home would bring to them, but those problems did not impact their decision. Family members grappled with the planning and the complex skills that had to be mastered before the older adults could be discharged home. HCTMs revealed their struggles and concerns about discharging frail older adults. The problems inherent in discharge planning have been exhaustively discussed throughout the last decade (Naylor et al., 1999; Naylor et al., 1994) and yet the problem remains.

Hospitals can and must improve their early communication about anticipated hospital discharge with patients and families. Problems with communication in hospitals have been discussed extensively and implicated as the main impediments to patient safety in hospitals (Kohn, Corrigan, Donaldson, 2000). The Centers for Medicare and Medicaid (CMS) have recently revised their rules for notifying a beneficiary (older adult) of their proposed discharge date (Medicare Program Proposed Rule, 2006). The notification of discharge date must occur within two calendar days of admission. If the patient disagrees with the proposed plan for discharge, they have the right to request a review of the discharge plan by the Quality Improvement Organization (QIO). However, many hospital stays are short, and patients may feel too vulnerable to professional dominance to call the QIO while still hospitalized. Poor communication in hospitals continues to be one of the most persistent and difficult problems to address in health care.

Patients and their family members in the present study were willing to work with the HCTMs to explore and discuss important issues of how to care for their frail older family member. Patients are often discharged very quickly from the hospital, making it even more important to effectively and efficiently involve them and their family members in early discussions about their ongoing care needs. HCTMs must find innovative ways to bring the health care team to the patient’s bedside, and remove clinical team discussions about patients from the hallways and nurses stations of hospitals, where patients are not included in the conversation. Anderson and Mangino (2006) recommended that nurse end-of-shift reports occur at patients’ bedsides. This allowed nurses who were leaving their shift, those coming on duty, patients, and families to talk together about the patient’s health status, their goals for the day, and to address questions.

Similar to nurse end of shift report, another valuable intervention would be walking team rounds. Walking team rounds enable the entire health care team to assess the patient and address issues and concerns together with the patient and their family. Walking team rounds would also help to reduce inconsistent reports that are often given to patients and their family members about the patient’s medical condition by HCTMs (Counsel & Guin, 2002; Kirchoff, 2002; Puopolo et al., 1997). However, getting physicians and other HCTMs to make rounds at the same time may be very challenging. But it should be possible for the patient’s primary physician and representative members of the health care team to make rounds daily to address problems in the discharge plan.

This is not a new intervention, but it is being emphasized once again, because medical professionals do not routinely include patients in discussions about their care early enough in the process. When patients are not drawn into conversations, they eventually stop communicating about their health needs (Paterson, 2001). It is certainly possible that patients did not tell HCTMs what needed to be done to make their home situation more workable, because they feared the reaction of the HCTM. The present study found patients and family member’s fears about how HCTMs respond were justified. Patients want to be included in health care decision-making not directed by others (Davison et al., 1995; Davison et al, 2002; Degner, & Sloan, 1992).

Open communication is essential. If HCTMs suspect the patient will not be able to go from hospital to home immediately upon discharge, they have an obligation to outline with the patient and their family the pertinent issues that concern them. A patient may still insist on going home against the advice of the health care team, but if plans are put in place early enough, the patients' care needs may be better met. HCTMs must also find ways to efficiently assess patients' and family members' capacity to give care. Current research continues to show nurses do not routinely assess the functional status of older patients, but predominantly rely on verbal information from the patient about how they function (Reiley, Iezzoni, hillips, Davis, & Tuchin, 1996). Furthermore, when frail spouses are the primary caregivers, it may be equally important to establish their capacity to give care. The current model of discharge planning relies solely upon the clinical judgment of HCTMs. Finding a way to assess caregiving capacity in a more deliberate way, may make conversations about potential problems about going home from the hospital easier. Capacity assessment should involve both cognitive and functional capacity.

By including patients and family members in the process early, potential communication problems about the discharge are reduced. The role of the social worker is vital to assist with the support for stressed families and the management of the complex problems that are so frequently found in frail older adults. Professional nurses need to continue to develop the outcomes coordination model in hospitals. The present study identified that outcome coordinators and social workers had distinct, but complementary roles. Patients who are frail, old, and chronically ill often have frequent admissions to the hospital. It would be helpful to assign them a consistent hospital outcomes coordinator, who is knowledgeable about their specific needs. In turn, the outcomes coordinator can address those needs concisely and coherently with the other members of the health care team from the day of admission forward.

Future Research

This research will inform future work about how decisions are made in family groups with or without HCTMs' involvement. Each type of decision is unique, and decisions about hospital discharge destinations are crucially important as the present study has illustrated. Pierce and Hicks (2001) evaluated the state of science in research about patient decision-making behavior and identified that work needs be done to provide descriptive models of decision-making behavior for specific populations under varying conditions. The present study has laid the foundation for future work in the area of discharge destination decision-making for frail older adults, family members, and HCTMs by identifying that decisional congruence among members of triads occurs even when preference for LOP is not met. Also, triads work and communicate well together unless certain issues exist such as (a) concern for safety, (b) lack of open communication, and (b) there are unmet needs for practical assistance in the home.

The present study has shown that congruence was more than agreement between preferred and actual LOPs in hospital discharge destination decisions. The meaning of individual decisional congruence needs more investigation with different decision-making decisions, under varying conditions. It would be useful to understand more about the decision-makers value and belief structure and the influence of the power of health care professionals on decisional congruence. More explication of internal, external, and system influence is needed.

More understanding about the processes used by frail older patients and multiple family members to make decisions about hospital discharge is needed. Patient and family member interviews should be done individually and conjointly, to elicit a full range of responses about health care decision-making. The information obtained from individual interviews may vary from that obtained in conjoint interviews.

It would be useful to know more about how health information from multiple HCTMs is used by the patient and family. It will be important to also understand if the patient reaches a point where they have received too much information, and how this might affect decisional congruence.

The CPS scale used for the present study would benefit from validity and reliability testing. The instrument did not perform as expected in frail older adults and it will be necessary to identify if there needs to be revision of wording of CPS across the triad. The reworded CPS would need validity testing. Testing would include obtaining expert content validity, test-retest, and think aloud protocols.

It will remain critically important to elicit the viewpoints of patients, families, and HCTMs in situations were there is disagreement with one another about health care decisions. A naturalistic study design would allow the investigator to attend care conferences and patient meetings, but would not involve activities that staff members would perceive as intrusive.

Health care teams do not always agree how best to approach potentially contentious issues, such as patients insisting on going home when HCTMs are not in agreement with that decision. In the present study, if patients were going home, but were perceived to be unsafe by the HCTMs a hotline call was made to Missouri's Department of Health and Senior Services (DHSS) for self-neglect. There is no literature that addresses the issue of hospital personnel using the Elderly Abuse and Neglect Hotline as way to help ensure patient safety at home after hospital discharge. More understanding about this phenomenon is needed. It would be useful to know how many patients are "hotlined" by hospitals statewide. One approach to this problem is to request from the State of Missouri, DHSS, records of calls from hospitals to the Elderly Abuse and Neglect Hotline. Hospitals that often use the hotline system could be selected for further investigation. Once it is known which hospitals commonly use the hotline, more details can be obtained using focus groups, interviews, or questionnaires about why patients are "hotlined."

Communication about preparing for hospital discharge often occurs in discharge planning teams. The focus of discharge planning research has been to identify how to improve outcomes related to hospital discharge. The process of discovering how discharge teams work together with patients and family members has been largely ignored by scientists. The issue of why patients are not more involved in the key decisions related to discharge is puzzling. Perhaps the answer to the puzzle lies in understanding more about how discharge planning teams actually function and to rely less on the rhetoric about how they are supposed to function.

It would be useful to develop a capacity assessment tool to assist HCTMs to work more effectively with frail older adults and their family members. A capacity assessment tool would include assessments for both cognitive and physical capacity.

To the investigators knowledge, there is nothing in the literature about capacity assessment to prepare for hospital discharge. It will be necessary to do a literature review to establish what has been done in capacity assessment to prepare for hospital discharge. It also would be useful to have series of focus groups with registered nurses, outcomes coordinators, and social workers who could identify issues that could be assessed with such a tool.

Conclusion

The single most striking finding in the present study was that individual decision-making congruence was not related to congruence of the triad. Decisions between older adults, family members and HCTMs occur hundreds of times a day in hospitals throughout the United States. These decisions may be simple decisions that do not involve life altering changes. Often decisions made in health care settings are not simple and the end result of these decisions mean significant changes to the lives of patients and their families. These life altering decisions not only include where to go after hospital discharge, but also the emotionally difficult choices that accompany deciding to remove or continue life support, to continue or stop treatment for a chronic illness, or decide to be or not to be resuscitated in the event of death. Most of these complex and emotionally difficult decisions are made among families members, who are facing horrifically difficult choices, and health care professionals who are encumbered by the constraints of a care system that allows them little time to build relationships with patients and their families. There is a significant need to understand both theoretically and in a practical sense, how patients and their families work with HCTMs to make health care decisions.

Appendix 1 Short Mini Mental State Exam

Study ID number_______
Date___________

Short Mini Mental State Exam

I would like to ask you some questions that ask you to use your memory. I am going to name three objects. Please wait until I say all three words, and then repeat them. Remember what they are because I am going to ask you to name them again in a few minutes. Please repeat these words for me: APPLE – TABLE- PENNY. (Interviewer may repeat three times if necessary but repetition not scored.)

1. What year is it? _________(1)
2. What Month is it? _________(1)
3. What is the day of the week? _________(1)

What are the three objects I asked you to remember?

4. Apple _________(1)
5. Table _________(1)
6. Penny _________(1)

Score 1 for each correct answer and 0 for incorrect answers.

Total Score _________

Appendix 2, Frailty Phenotype Instrument

Frailty Phenotype Study ID#______________

Date__________________

Before beginning ask participant for their:
Height in inches_______x 2.54= ____ (height in cm)
Weight in pounds_____ ÷ 2.2 = ____ (weight in kg)

1. Weight loss: "In the past year have you lost more than 10 pounds unintentionally (i.e. not due to dieting or exercise)? Yes No
   If yes, than positive for weight loss criteria. _______

2. Exhaustion: I am going to read you two statements that are followed by the responses. Please answer what comes closest to how you feel.
   a. I felt that everything I did was an effort. How often in the last week did you feel this way?
      0 = Rarely or none of the time (<1 day)
      1 = Some or little of the time (1-2 days)
      2 = A moderate amount of time (3-4 days)
      3= Most of the time
   b. I could not get going. How often in the last week did you feel this way?
      0= Rarely or none of the time (<1 day)
      1 = Some or little of the time (1-2 days)
      2 = A moderate amount of time (3-4 days)
      3= Most of the time

   If participants answer 2 or 3 to either question than positive for exhaustion criteria____

3. In a typical week, how many hours a week did you do any of the following activities?
   Formula is: Kcal=METs x hours of activity x kg body weight
   Example is: Kcal/week expended for walking slowly or household walking for 6 hours per week
   Kcal/week= 3.0 x 6 hours x 70 kg = 1260
   a. Walking………… ____ = MET_____ x ____x____=____
   b. Household chores..____ = MET_____ x ____x____=____
   c. Moving the lawn...____ = MET_____ x ____x____=____
   d. Raking………….. ____= MET_____ x ____x____=____
   e. Gardening………____= MET_____ x ____x____=____
   f. Hiking…………...____= MET_____ x ____x____=____
   g. Jogging…………____= MET_____ x ____x____=____
   h. Biking…………...____= MET_____ x ____x____=____
   i. Exercise Cycling..____ = MET_____ x ____x____=____
   j. Dancing…………____= MET_____ x ____x____=____
   k. Acrobatics………____= MET_____ x ____x____=____
   l. Bowling…………____= MET_____ x ____x____=____

m. Golf……………____= MET_____ x ____x____=____
n. Singles Tennis….____= MET_____ x ____x____=____
o. Doubles Tennis…____= MET_____ x ____x____=____
p. Racquetball…….____= MET_____ x ____x____=____
q. Calisthenics…….____= MET_____ x ____x____=____
r. Swimming………____= MET_____ x ____x____=____
Add a-r for Kcal expended per week _________
Men: Kcals of physical activity per week <383 are frail______
Women: Kcals per <270 are frail______

4. Walk time, stratified by gender and height:

Men:	Cutoff for time to walk 15 ft criterion for frailty
Height ≤ 173	≥ 7 seconds
Height > 173	≥ 6 seconds
Women	
Height ≤ 159	≥ 7 seconds
Height > 159	≥ 6 seconds

If cutoff score for walk time not met or if unable to ambulate than positive for walk time criteria.________

5. Grip Strength, stratified by gender and BMI quartiles:
   a. BMI: Body weight in pounds x 705 ÷ (height in inches)^2 =______

Men	Cutoff for grip strength criterion for frailty
BMI ≤ 24	≤ 29
BMI 24.1-26	≤ 30
BMI 26.1-28	≤ 30
BMI > 28	≤ 32

Women	Cutoff for grip strength criterion for frailty
BMI ≤ 23	≤ 17
BMI 23.1 - 26	≤ 17.3
BMI 26.1 – 29	≤ 18
BMI > 29	≤ 21

If cutoff score for grip strength not met than positive for grip strength criteria._______

Total points_____
Positive for frailty phenotype if ≥ 3 criteria present
Intermediate or prefrailty: 1 or 2 criteria are present

Appendix 3, Demographic Questionnaire Frail Older Adult

Study ID#______________
Date__________________

How old are you?

Sex: Male_____Female______

What happened that you were admitted to the hospital?

What other illnesses or conditions do you have?

What is your race?
______Caucasian
______African American
______Hispanic
______Asian
______Native American
______Other, please specify________

How many years did you attend school?
_____Less than high school
_____How many years of HS completed
_____Some College
_____College graduate
_____Post Graduate degree

Are you married?
_____Married
_____Widowed
_____Divorced
_____Lives with a partner
_____Never married

How many children do you have?

Are they all living?

Do you live with anyone else?

In what way does that person help you?

Does anyone help you with the following activities?
___Getting dressed
___ Taking a bath
___Getting to the toilet
____Grocery shopping
____Other Shopping
____Housekeeping
____Yard work
____Paying bills
____Getting to appointments

Does anyone help you in ways that we have not talked about?

Appendix 4, Demographic Questionnaire Family

Demographic Questionnaire Family

Study #____________

Date #_____________

How old are you?

Sex: Male_____Female______

What is your race?

______Caucasian

______African American

______Hispanic

______Asian

______Native American

______Other, please specify________

How many years did you attend school?

_____Less than high school

_____How many years of HS completed

_____Some college

_____College graduate

_____Post Graduate degree

Are you married?

_____Married

_____Widowed

_____Divorced

_____Lives with a partner

_____Never married

Does your family live with someone else?

___Spouse

___Friend

___Child

___Other family member

___Paid Caregiver

___Other

In what way does that person help your family member?

To your knowledge does anyone help your family member with any of the following activities?
____Getting dressing
____Taking a bath
____Getting to the toilet
____Grocery shopping
____Other Shopping
____Housekeeping
____Yard work
____Paying bills
____Getting to appointments

Appendix 5, Demographic Questionnaire HCTMs

Study ID#________

Date______________

What is your age?

Sex: Male_______Female_______

What is your race?
______Caucasian
______African American
______Hispanic
______Asian
______Native American
______Other, please specify________

What is your profession?
______Nurse LPN
______Nurse ADN
______Nurse BSN
______Nurse Diploma
______Social Work, Bachelors
______Social Work, Master
______Advanced Degree, if yes in what field?

Specific position held?

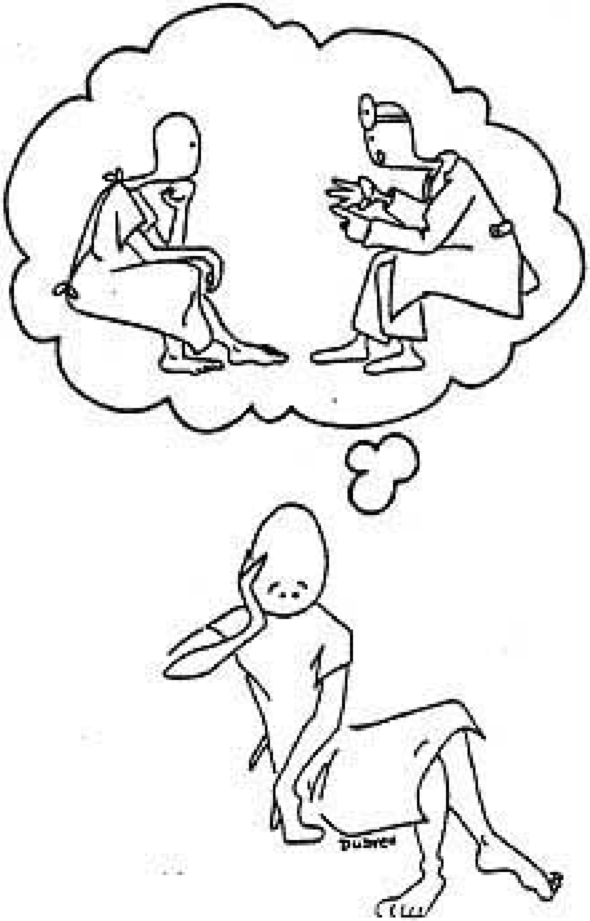
______Floor Nurse
______Care Coordinator
______Social Worker

Number of years you have worked in your profession?

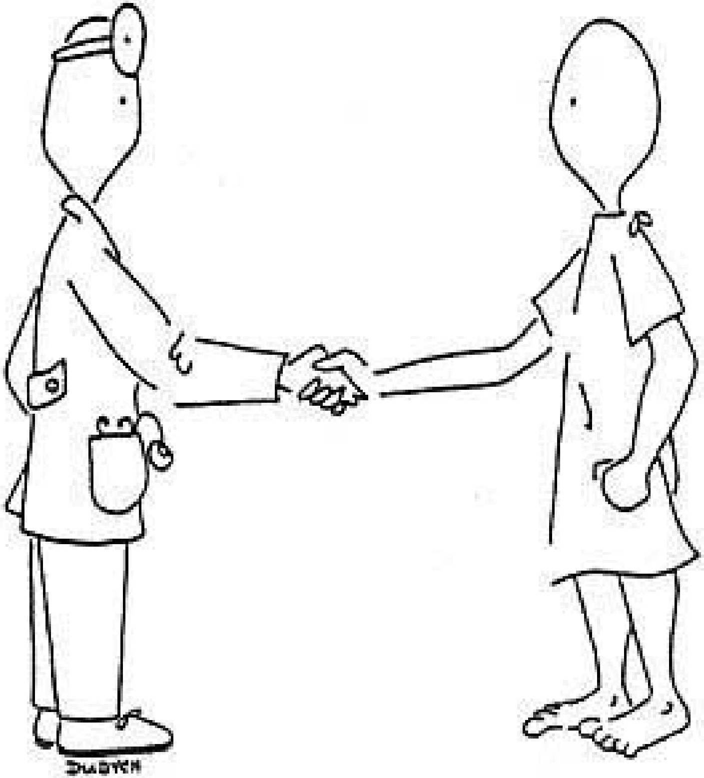
Type of positions held in the last 5 years?

Appendix 6, Discharge Destination CPS Cards Frail Older Adult

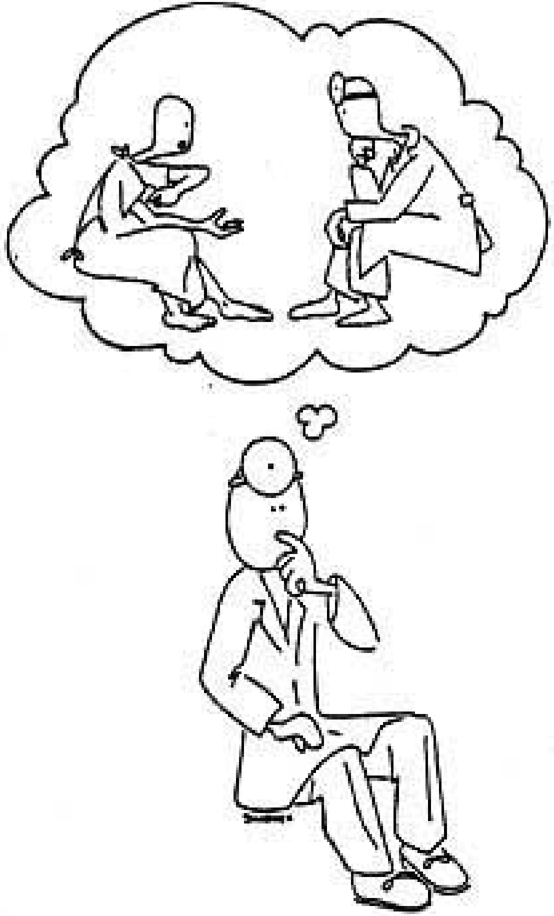
I prefer to make the final decision about where I will go after hospital discharge.



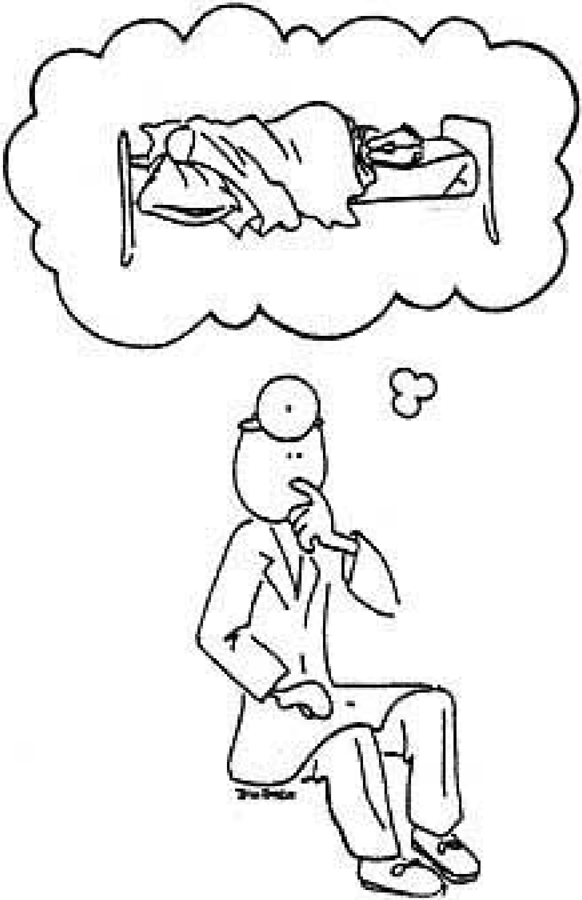
I prefer to make the final decision about where I will go after hospital discharge after seriously considering the health care team and my family's opinion.



I prefer that the health care team, my family, and I share responsibility for deciding where I will go after hospital discharge.



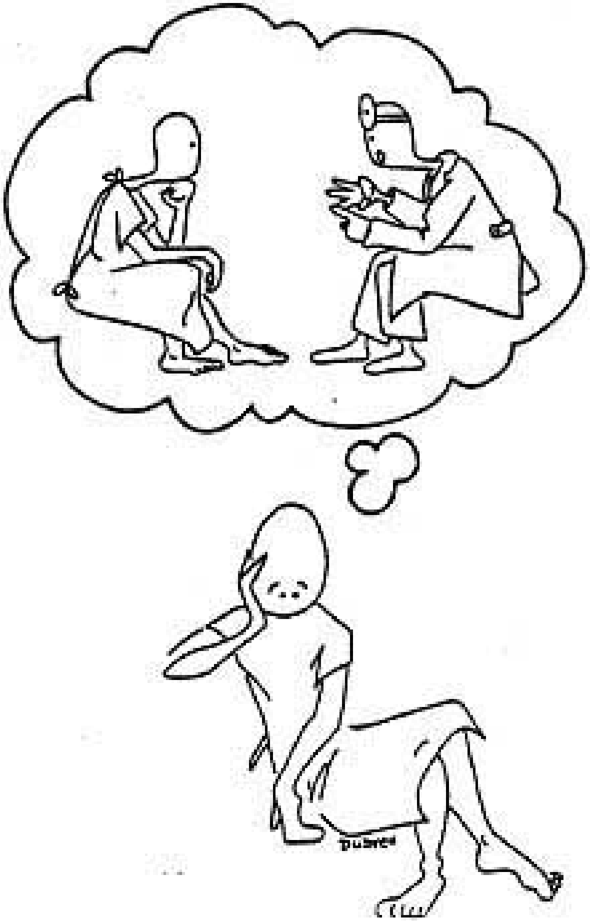
I prefer that the health care team and my family make the final decision about where I go after hospital discharge after they seriously consider my opinion.



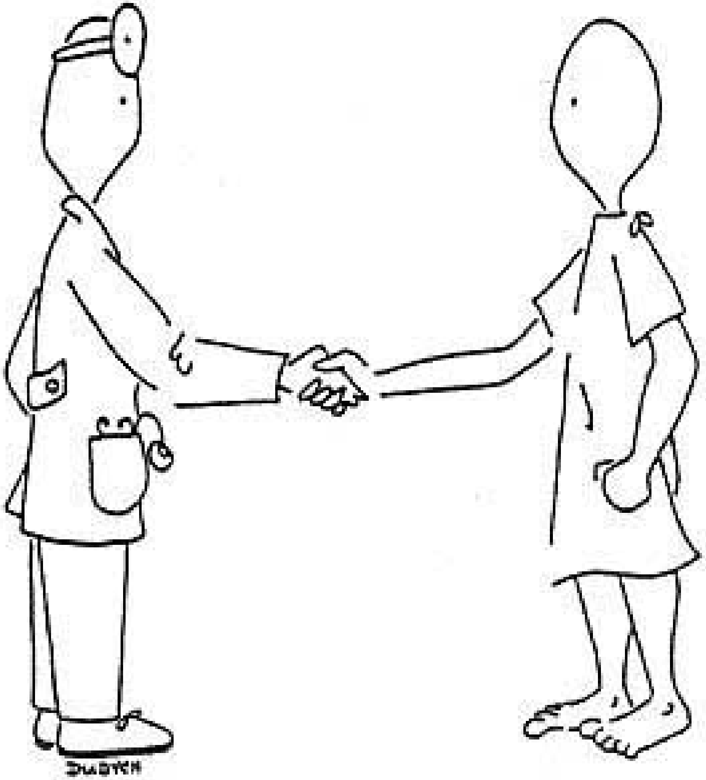
I prefer to leave all
decisions regarding where
I go after hospital discharge
to the health care team and
my family.

Appendix 7, Discharge Destination CPS Cards Family Members

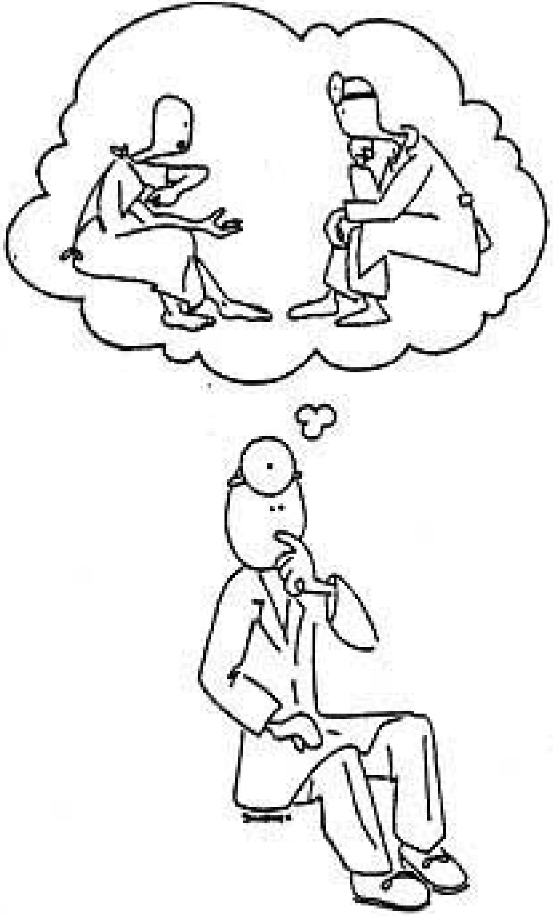
I prefer that I make the decision for ____________________ about where they will go after hospital discharge.



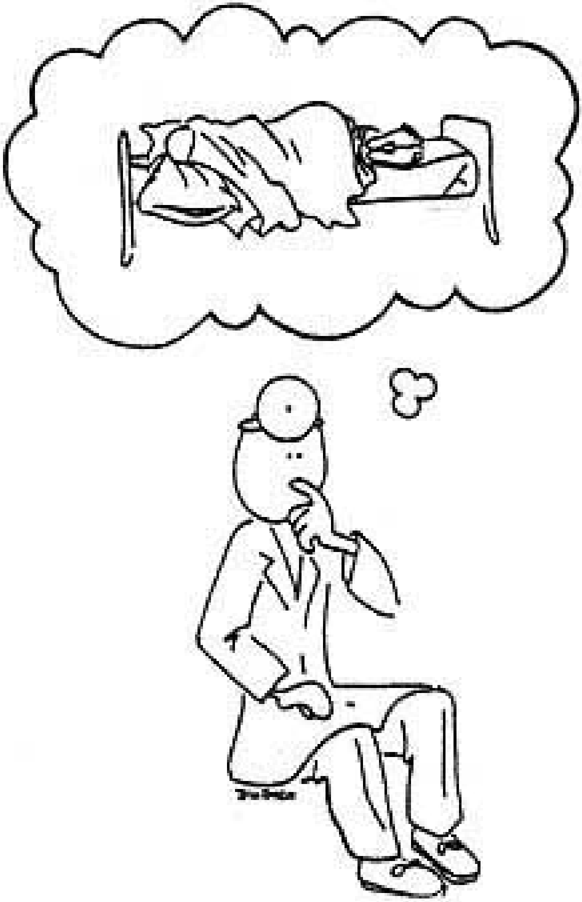
I prefer to make the final decision about where ____________________ will go after hospital discharge after seriously considering the health care team and ________________ opinion.



I prefer that _______________,
the health care team, and I
share the responsibility for
deciding where I will go after
hospital discharge.



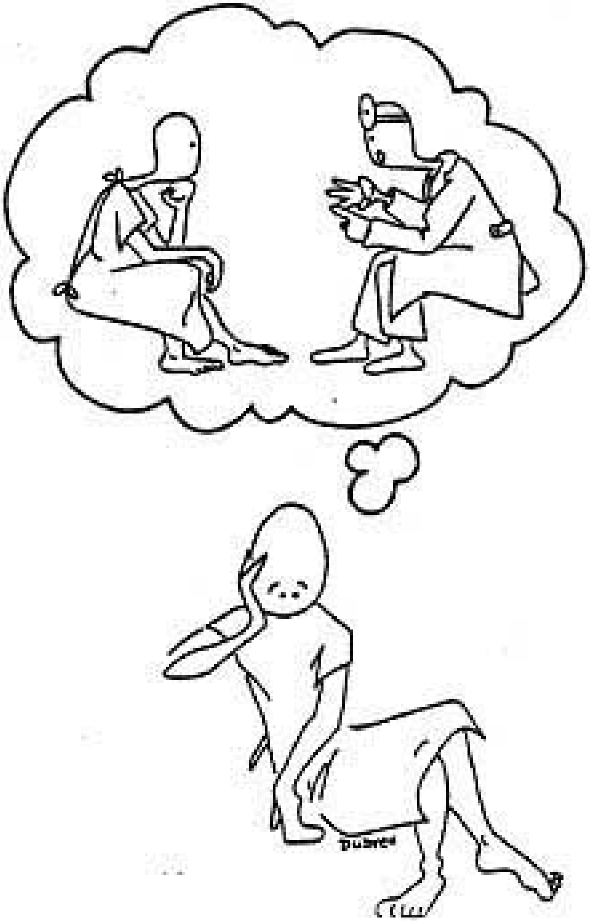
I prefer that ________________
and the health care team make
the final decision about where
________________ will go after
hospital discharge, but that they
seriously consider my opinion.



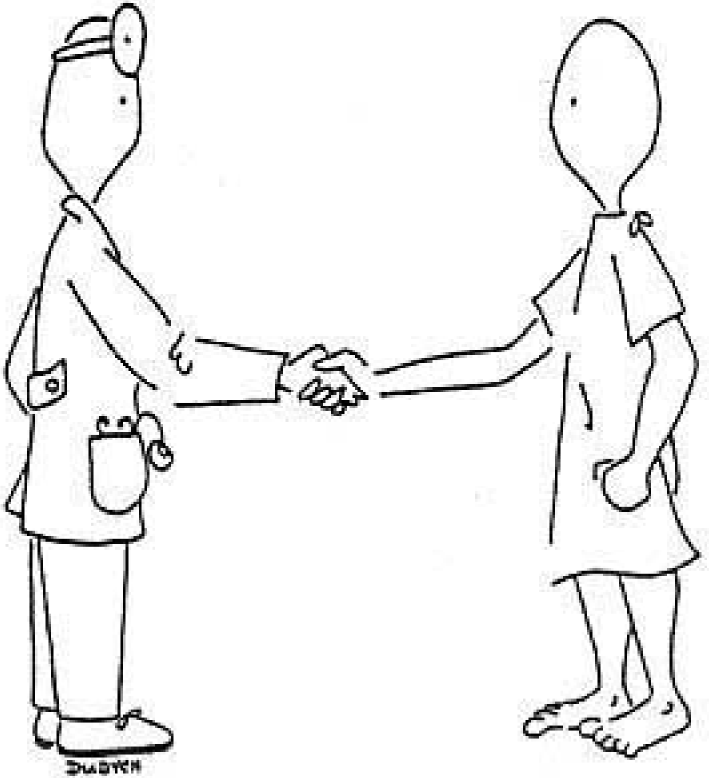
I prefer to leave all decisions regarding where ____________________ will go after hospital discharge to them and the health care team.

Appendix 8, Discharge Destination CPS Cards HCTMs

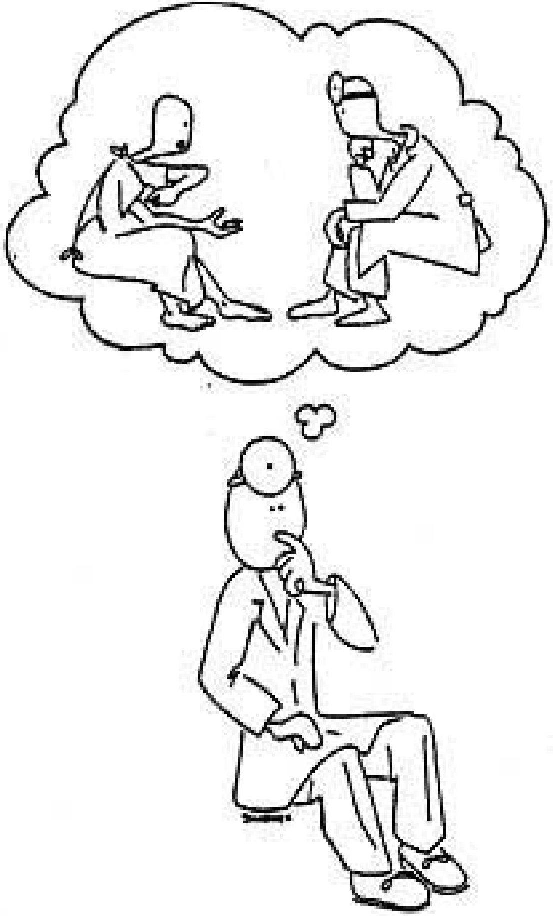
I prefer that I make the decision for the patient about where they will go after hospital discharge.



I prefer to make the final decision about where the patient will go after hospital discharge after seriously considering my patient's and their family's opinion.



I prefer that my patient,
their family, and I share
responsibility for deciding
where they will go after
hospital discharge.



I prefer that my patient make the final decision about where they will go after hospital discharge, but seriously consider their family's and my opinion.

Appendix 9, Interview Guide Frail Older Adult

Study ID #_______
Date____________

Interview Guide Frail Older Adults
Frail older adult guided questions:

You are preparing to leave the hospital. I would like to know more about your decision about where to go after hospital discharge. I am also interested in knowing about any concerns or worries you may have about leaving the hospital. I will be tape-recording the conversation so that I can review it later and relate your experiences to that of others who I will be interviewing. It is your right to decline to answer any question or to end this interview at any time.

1. You and your family are currently making decisions about leaving the hospital. What choices did you consider about where to go after discharge?

2. What is your final choice about where to go?

3. Going home after an illness can be rather complicated. Are there other things that you had to consider before your making your choice about where you would go? Probes:
    - Please tell me what things needed to be taken care of before you leave the hospital?
    - What kind of services (like home health, rehabilitation, nursing home, or outpatient therapy) needed to be arranged?
    - What kind of equipment or supplies needed to be arranged?
    - Were there any other arrangements that needed to be made?
    - What decisions need to be made before you can leave?
    - Who is involved in the decision(s)?

5. You have been working with other people, your family, doctor, nurses, or social worker, as the decision has been made about where to go after leaving the hospital. Can you tell me about your experiences with working with others as you have made this decision about hospital discharge
   Probes:
   - What were the issues that you or your family didn't totally agree about?
   - What were the issues that you, or your doctors, nurses, or social workers didn't totally agree with about?

6. Is there anything else you would like to tell me?

Appendix 10, Interview Guide Family Members

Interview Guide Family Members Study ID #________
Date_____________

Family member guided questions:
You have been identified by _________ as a family member who is helping them to make decisions about leaving the hospital. I would like to know about any worries or concerns that you may have about your family member leaving the hospital. I will be tape-recording the conversation so that I can review it later and relate your experiences to those of others who I will be interviewing. It is your right to decline to answer any question or to end this interview at any time.

1. You and your family are currently making decisions about where he or she will go leaving the hospital. What choices did you consider about where to go after discharge?

2. What is the final choice about where to go?

3. Going home after an illness can be rather complicated. Are there other things that you and (<u>insert patient name</u>) had to consider before making the choice about where to go after discharge?
   Probes:
   - Please tell me what things needed to be taken care of before (<u>insert patient name</u>) leaves the hospital?
   - What kind of services (like home health, rehabilitation, nursing home, or outpatient therapy) needed to be arranged?
   - What kind of equipment or supplies needed to be arranged?
   - Were there any other arrangements that needed to be made?
   - What decisions need to be made before your family member can leave?
   - Who is involved in the decision(s)?

4. You have been working with other people, your family, doctor, nurses, or social worker, as you helped your family member make the decision about where to go after leaving the hospital. Can you tell me about your experiences with working with others as you have made this decision about hospital discharge?
   Probes:
   - Were there any issues that your family member didn't agree with you about?
   - Were there any issues that the doctor, nurses, or social workers didn't agree with you about?

5. Is there anything else you would like to tell me?

Interview Guide HCTMs

Study ID #________
Date____________

Health Care Team Member guided questions:

You have been identified by _________ as a health care team member who has been most involved in helping them to make decisions about leaving the hospital. I would like to know about the experience of helping a frail older patient and their family make decisions about where to go after leaving the hospital. I will be asking you about the experiences you have had with your patient and their family as you have helped them make plans to leave the hospital. I am particularly interested in any concerns or worries you may have about the discharge destination decisions made by this patient and their family. I will be tape-recording the conversation so that I can review it later and relate your experiences to those of others who I will be interviewing. It is your right to decline to answer any question or to end this interview at any time.

1. What is your role with this patient and their family?

2. Who else is working with the patient and their family about discharge planning?

3. You are currently working with the patient and the family to make decisions about leaving the hospital. What choices did the patient and family consider about where the patient will go after hospital discharge?

4. What is the final choice about where to go and why?

5. Are there things that the patient and their family had to consider before making the choice about discharge destination?
   Probe:
   - Please tell me what things needed to be taken care of before the patient and their family leave the hospital?
   - What kind of services (like home health, rehabilitation, nursing home, or outpatient therapy) needed to be arranged?
   - What kind of equipment or supplies needed to be arranged?
   - Were there any other arrangements that needed to be made?
   - What decisions need to be made before your patient can leave?
   - Who is involved in the decision(s)?

6. You have been working with the patient, their family and the doctor as your patient made the decision about where to go after leaving the hospital. Can you tell me about how you were you able to work with these people about your hospital discharge decision?
   Probes:
   - Were there any issues that the patient didn't agree with you about?

- Were there any issues that the family member didn't agree with you about?
- Were there any issues that other members (doctor, nurses, or social workers) didn't agree about?

7. What else would you like to tell me?

Appendix 12, Study Consent Frail Older Adult

Hospital Discharge Decisions: How Frail Older Adults, Their Family, and Health Care Teams Make Decisions

A study to be conducted at Boone Hospital Center

This consent form may contain words that you do not understand. Please ask the study investigator or the study staff to explain any words or information that you do not clearly understand.

1. <u>Why is this research being done?</u>

   You are being asked to take part in a research study. Research studies include only people who choose to take part. As a study participant you have the right to know about the procedures that will be used in this research study so that you can make the decision whether or not to participate. The information presented here is simply an effort to make you better informed so that you may give or withhold your consent to participate in this research study.

   This study is a dissertation research project and is the final project for my doctorate in nursing. If you want to participate in this study, you need to sign a consent form. It is important for you to take your time to make your decision and discuss it with your family and friends.

   The purpose of this study is to see how hospitalized frail older adults, their family, and a hospital staff member each want to take part in the decision about where the older adult will go after they get out of the hospital. I also want to learn about how they work together to make the decision.

   You are being asked to take part in this study because you are deciding where you will go when you get out of the hospital. I will also be talking with a family member that you recommend, and one of the hospital staff members who have been helping you with this decision. I will ask them questions that are a lot like the ones that I will ask you.

   This research is being done because we know very little about how frail older adults and their families work with hospital staff to make this decision. Older adults often get out of the hospital very quickly, while they are still weak or sick. If we can learn more about how frail older adults and their families work with hospital staff, then maybe we can prevent problems, like unexpected return to the hospital, or not having enough help at home.

2. If you volunteer, you will take part in this study for 2 days until all the information is collected. About 60 people (20 older adults, 20 family members, and 20 health care team members) will take part in the study at Boone Hospital Center.

3. Taking part in this study is completely voluntary. You are free to decide not to participate. If you begin the study, you can change your mind at any time and stop

participating. Your choice will not affect your relationship with your doctor, staff who care for you, or Boone Hospital Center, and it will not affect the standard of care that you receive. There are no risks to quitting the study.

I may decide to take you out of this study if your health suddenly gets worse so that you have to go to an intensive care unit for more than 24 hours or if you go home before the study is finished.

4. What is involved in the research?

To be in the study you must be close to the time when you will be deciding where to go when you get out of the hospital. This will most likely be within 48 hours of leaving the hospital. You must also have family member who is helping you with decisions who is also willing to be in the study. I will ask you if you are working with a specific nurse, care coordinator, or social worker about where you will go after you get out of the hospital. If you don't know which health care staff member is helping you, I will ask the nurse, care coordinator, or social worker to participate that knows you best.

I will be asking you a few simple questions to make sure that you are thinking clearly enough to be in the study. If you are confused, I will not ask you for any more information. To see if you are frail, I will be asking you to answer some simple questions about your activities at home, watch you walk a short distance, and test your grip strength. If you can't get out of bed without help, you will not be asked to walk. If I find that you are not frail, I will not ask you any more questions. These two activities should take no more than 20-30 minutes.

If I find that you are not confused, that you meet the minimal criteria for being frail, and that you have a family member willing to participate I will ask you to do the final three activities. These activities include having you complete a simple questionnaire to help me understand more about you, such as your age, if you are married, and whom you live with. I will next ask you look at cards that show how much participation you want when making decisions. Finally, I will be asking you a few questions about your decision about where to go after you get out of the hospital and what it was like for you to work with other people as you made this decision. This part of the study should take no more than 45 minutes unless you have a lot to say to me when we are talking.

5. You will be told about any new information that might affect your willingness to continue to take part in this study.

6. What are the risks of the study?

There are few risks of being in the study. You could fall or get hurt when you do the walking part of the frailty test. To protect you from this, if you are unsteady, cannot get out of bed without help, or your nurse thinks that you cannot safely walk, then I won't ask you to do the walking part of the test. The second risk is that you could get tired during interview. To protect you from this risk, I will ask you after each test if you feel well enough to continue. If you are too tired to continue we will stop and plan another time to continue. The third risk is that talking about where you go after you leave the hospital may lead you to make a different choice, which may delay your discharge.

For these reasons, I will pay close attention to you while doing the tests and the interview. If you are concerned about any of the things that I have described to you, please let me know immediately. You can call me at 573-445-2354 or 573-815-8428.

7. Are there benefits to taking part in the study?
If you agree to be in this study, there may or may not be direct benefit to you. We hope the information learned from this study will benefit other patients and their families who are making
decisions about discharge from the hospital in the future. Other benefits may include having the opportunity to tell someone about your experiences with hospital discharge.

8. What other options are there?
If you decide not to take part in this study, it will in no way affect the discharge planning you will receive from the doctors, nurses, and social workers who are working with you and your family. I am not interested in changing your decision about where to go after discharge, but am interested in understanding more about how the decision was made.

9. What are the costs?
There is no cost to you for participating in the study.

You will not be paid for taking part in this study.

10. The investigator is a doctoral student at Sinclair School of Nursing-University of Missouri and receives no payment for this study.

11. What about confidentiality?
Information that you give me will be stored in my files and identified by a code number only. The code key connecting your name to specific information about you will be kept in a separate, secure location. Information contained in your records may not be given to anyone not connected with the study in a form that could identify you without your written consent, except as required by law.

It is possible that your research record, including sensitive information and/or identifying information, may be inspected and/or copied by the Boone Hospital Center and University of Missouri Health Sciences Institutional Review Boards, federal or state government agencies, or hospital accrediting agencies, in the course of carrying out their duties. If your record is inspected or copied by the by any of these agencies, Boone Hospital Center and the University of Missouri will use reasonable efforts to protect your privacy and the confidentiality of your medical information.

The results of this study may be published in a medical book, journal, used in research presentations, or for teaching purposes. However, your name or other identifying information will not be used in any publication, presentation, or teaching materials without your specific permission.

12. Additional concerns
If you are injured in any way as a result of taking part in this study, you may contact Lori Popejoy at 573.815.8428 or 573.445.2354. She will make every effort to address problems caused by the study. If taking part in this study results in physical injury or illness, medical treatment will be made available to you. There are no funds for compensation set aside for research-related injuries. However, by signing this form, you do not give up any of your legal rights for compensation.

13. The procedures in this study may have risks, and it is not the policy of Boone Hospital Center to compensate for injury resulting from the study treatment or other procedures. The hospital has insurance coverage for injury caused by negligence. If you believe you have suffered injury as a result of your participation in this study, you may contact the Quality/Risk Management Coordinator, at (573) 815-3762.

14. Questions
Please ask any questions you have about this research and Lori Popejoy will answer them. If you decide to volunteer and have questions later on during your participation, please feel free to ask them. Make sure that all your questions are answered to your satisfaction. If you have any questions or problems, please call Lori Popejoy at 573.815.8428 during the day or 573.445.2354 in the evening.

15. If you have questions about your rights as a research subject, you may contact the IRB chairman, David Brummett, MD, at (573) 815-8000.

16. Personal health information
By signing this form, you give the investigators involved in this study the right to use and disclose your personal health information as it is necessary to carry out and complete the research. Personal health information that will be used and disclosed may include your name , age, reason for hospitalization, illnesses, ability to take care of yourself at home, mental status scores, and frailty scores. Once your personal health information has been disclosed to other organizations and persons, it may not be protected by federal and state privacy regulations. While every effort will be made to keep your personal health information confidential, your information may be used and disclosed as follows:
    - to others involved in the research;
    - as required by law, such as to government agencies like Health and Human Services, that oversee how the study is conducted;
    - to the Institutional Review Board (IRB) of Boone Hospital Center and Health Sciences IRB at the University of Missouri;
    - in publications, presentations, or reports about the study; however, your name and other identifying information will be removed.

17. Your authorization (consent) for the use and disclosure of your personal health information applies until this study is finished. You may revoke (take back) your authorization to use and disclose your personal health information at any time. This revocation must be in writing and will not apply to any health information about you that has already been used or disclosed. If you revoke your consent to use and

disclose your personal health information, then you may not be eligible to continue to participate in the study.

18. You will have the opportunity to receive a copy of the "Notice of Privacy Practices" from your doctor and Boone Hospital Center that explains when, where, and why your personal health information may be used or shared by the hospital. You will also receive a copy of this form.

19. In order to take part in this study, you will need to give your written consent. You may change your mind and withdraw your consent at any time.

I consent to participate in this study. I also authorize the investigator and Boone Hospital Center to use and disclose my personal health information to the extent necessary to carry out and complete the research. My consent is given freely, and I have read (or have had read to me) and understand the explanation of my rights in the summary above. I am satisfied with the explanation of the study contained in the summary above, and I have had all of my questions answered to my satisfaction. I understand that I am not required to sign this form or participate in this study. I understand that I may withdraw my consent at any time.

____ Patient	________________ Date
____ Investigator	________________ Date
____ Witness	________________ Date

RESEARCH SUBJECT'S BILL OF RIGHTS

You have been asked to participate as a subject in a clinical research procedure. Before you decide whether you want to take part in research procedures, you have the right to:

1. To be informed of the nature and purpose of the research;
2. To be given an explanation of the procedure to be followed in the medical research, and any drug or device to be used;
3. To be given a description of any discomforts and risks reasonably to be expected from taking part in the research;
4. To be given an explanation of any benefits reasonably to be expected from your participation in the research, as applicable;
5. To be given a disclosure of any appropriate alternative treatments that might be helpful to you, and their relative risks and benefits;
6. To be informed of medical care available to you if complications or side effects should occur;
7. To be given an opportunity to ask any questions concerning the medical research and the procedures involved;
8. To be instructed that you may change your mind and withdraw your consent at any time and that you may stop taking part in the research without adversely affecting your future care or relationship with your doctor;
9. To be given a copy of the signed and dated written consent form; and
10. To be given the opportunity to decide to consent or not to consent to the research without any element of force, fraud, deceit, duress, coercion, or undue influence on your decision.

Appendix 13, Study Consent for Family Members

Hospital Discharge Decisions: How Frail Older Adults, Their Family, and Health Care Teams Make Decisions

A study to be conducted at Boone Hospital Center

This consent form may contain words that you do not understand. Please ask the study investigator or the study staff to explain any words or information that you do not clearly understand.

1. <u>Why is this research being done?</u>
   You are being asked to take part in a research study. Research studies include only people who choose to take part. As a study participant you have the right to know about the procedures that will be used in this research study so that you can make the decision whether or not to participate.

   This study is a dissertation research project and is the final project for my doctorate in nursing. If you want to participate in this study, you need to sign a consent form. It is important for you to take your time to make your decision and discuss it with your family and friends.

   You are being asked to take part in this study because you are helping a family member decide where they will go when they get out of the hospital. I will also be talking with your hospitalized family member and one of the hospital staff members who have been helping you with this decision. I will ask them questions that are a lot like the ones that I will ask you.

   The purpose of this study is to see how hospitalized frail older adults, their selected family member, and a hospital staff member each want to take part in the decision about where the older adult will go after they get out of the hospital. I also want to learn about how they work together to make the decision.

   This research is being done because we know very little about how frail older adults and their families work with hospital staff to make this decision. Older adults often get out of the hospital very quickly, while they are still weak or sick. If we can learn more about how frail older adults and their families work with hospital staff, then maybe we can prevent problems, like unexpected return to the hospital, or not having enough help at home.

2. If you volunteer, you will take part in this study for 2 days until all the information is collected. About 60 people (20 older adults, 20 family members, and 20 health care team members) will take part in the study at Boone Hospital Center.

3. Taking part in this study is completely voluntary. You are free to decide not to participate. If you begin the study, you can change your mind at any time and stop participating. Your choice will not affect your relationship with your family member's doctor, staff who care for your family member, or Boone Hospital Center, and it will not affect the standard of care that your family member receives. There are no risks to quitting the study.

I may decide to take you out of this study if your family member can no longer participate because their health suddenly gets worse and they have to go to an intensive care unit for more than 24 hours or if they go home before the study is finished.

4. <u>What is involved in the research?</u>
To be in the study your family member must be close to the time when they will be deciding where to go when they get out of the hospital. This will most likely be within 48 hours of leaving the hospital. I will also be asking your family member to identify a specific nurse, care coordinator, or social worker that has been working with them about where they will go after they get of the hospital. If your family can't identify which health care staff member is helping you, I will ask the nurse, care coordinator, or social worker to participate that knows your family member best.

I will ask you to answer a few questions about yourself such as how old you are, if you are married, and how many years of education you have. I will also have you look at cards that show how much participation you want when making decisions. Finally, I will be asking you a few questions about the decision about where your family member will go after they get out of the hospital and what it was like for you to work with other people about this decision. This part of the study should take no more than 45 minutes unless you have a lot to say to me when we are talking.

5. You will be told about any new information that might affect your willingness to continue to take part in this study.

6. <u>What are the risks of the study?</u>
There are few risks of being in the study. You could get tired during interview. To protect you from this risk, I will ask you after each test if you feel like you wish to continue. If you are too tired to continue we will stop and plan another time to meet. There is another risk that talking about where your family will go after you leaving the hospital may lead you and your family member to make a different choice.

For these reasons, I will pay close attention to you while doing the tests and the interview. If you are concerned about any of the things that I have described to you, please let me know immediately. You can call me at 573-445-2354 or 573-815-8428.

7. <u>Are there benefits to taking part in the study?</u>
If you agree to be in this study, there may or may not be direct benefit to you. We hope the information learned from this study will benefit other patients and their families who are making decisions about discharge from the hospital in the future. Other benefits may include having the opportunity to tell someone about your experiences with hospital discharge.

8. <u>What other options are there?</u>
If you decide not to take part in this study, it will in no way affect the discharge planning received from the doctors, nurses, and social workers who are working with you and your hospitalized family member. I am not interested in changing your decision about where to go after discharge, but am interested in understanding

more about how the decision was made.

9. <u>What are the costs</u>?
There is no cost to you for participating in the study.

You will not be paid for taking part in this study.

10. The investigator is a doctoral student at Sinclair School of Nursing-University of Missouri and receives no payment for this study.

11. <u>What about confidentiality?</u>
Information that you give me will be stored in my files and identified by a code number only. The code key connecting your name to specific information about you will be kept in a separate, secure location. Information contained in your records may not be given to anyone not connected with the study in a form that could identify you without your written consent, except as required by law.

It is possible that your research record, including sensitive information and/or identifying information, may be inspected and/or copied by the Boone Hospital Center and University of Missouri Health Sciences Institutional Review Boards, federal or state government agencies, or hospital accrediting agencies, in the course of carrying out their duties. If your record is inspected or copied by the by any of these agencies, Boone Hospital Center and the University of Missouri will use reasonable efforts to protect your privacy and the confidentiality of your medical information.

The results of this study may be published in a medical book, journal, or in research presentations for teaching purposes. However, your name or other identifying information will not be used in any publication or teaching materials without your specific permission.

12. <u>Additional concerns</u>
If you are injured in any way as a result of taking part in this study, you may contact Lori Popejoy at 573.815.8428 or 573.445.2354. She will make every effort to address problems caused by the study. If taking part in this study results in physical injury or illness, medical treatment will be made available to you. There are no funds for compensation set aside for research-related injuries. However, by signing this form, you do not give up any of your legal rights for compensation.

13. The procedures in this study may have risks, and it is not the policy of Boone Hospital Center to compensate for injury resulting from the study treatment or other procedures. The hospital has insurance coverage for injury caused by negligence. If you believe you have suffered injury as a result of your participation in this study, you may contact the Quality/Risk Management Coordinator, at (573) 815-3762.

14. <u>Questions</u>
Please ask any questions you have about this research and Lori Popejoy will answer them. If you decide to volunteer and have questions later on during your participation, please feel free to ask them. Make sure that all your questions are answered to your satisfaction. If you have any questions or problems, please call

Family Member

Lori Popejoy at 573.815.8428 during the day or 573.445.2354 in the evening.

15. If you have questions about your rights as a research subject, you may contact the IRB chairman, David Brummett, MD, at (573) 815-8000.

16. In order to take part in this study, you will need to give your written consent. You may change your mind and withdraw your consent at any time.

I consent to participate in this study. My consent is given freely, and I have read (or have had read to me) and understand the explanation of my rights in the summary above. I am satisfied with the explanation of the study contained in the summary above, and I have had all of my questions answered to my satisfaction. I understand that I am not required to sign this form or participate in this study. I understand that I may withdraw my consent at any time.

______________________________	______________
Patient	Date
______________________________	______________
Investigator	Date
______________________________	______________
Witness	Date

Appendix 13, Study Consent for Family Members

RESEARCH SUBJECT'S BILL OF RIGHTS

You have been asked to participate as a subject in a clinical research procedure. Before you decide whether you want to take part in research procedures, you have the right to:

1. To be informed of the nature and purpose of the research;
2. To be given an explanation of the procedure to be followed in the medical research, and any drug or device to be used;
3. To be given a description of any discomforts and risks reasonably to be expected from taking part in the research;
4. To be given an explanation of any benefits reasonably to be expected from your participation in the research, as applicable;
5. To be given a disclosure of any appropriate alternative treatments that might be helpful to you, and their relative risks and benefits;
6. To be informed of medical care available to you if complications or side effects should occur;
7. To be given an opportunity to ask any questions concerning the medical research and the procedures involved;
8. To be instructed that you may change your mind and withdraw your consent at any time and that you may stop taking part in the research without adversely affecting your future care or relationship with your doctor;
9. To be given a copy of the signed and dated written consent form; and
10. To be given the opportunity to decide to consent or not to consent to the research without any element of force, fraud, deceit, duress, coercion, or undue influence on your decision.

Appendix 14, Study Consent Health Care Team Members

Hospital Discharge Decisions: How Frail Older Adults, Their Family, and Health Care Teams Make Decisions

A study to be conducted at Boone Hospital Center

This consent form may contain words that you do not understand. Please ask the study investigator or the study staff to explain any words or information that you do not clearly understand.

1. Why is this research being done?

   You are being asked to take part in a research study. Research studies include only people who choose to take part. As a study participant you have the right to know about the procedures that will be used in this research study so that you can make the decision whether or not to participate.

   This study is a dissertation research project and is the final project for my doctorate in nursing. If you want to participate in this study, you need to sign a consent form. It is important for you to take your time to make your decision and discuss it with your family, co-workers, or supervisor.

   The purpose of this study is to see how hospitalized frail older adults, their family, and a hospital staff member each want to take part in the decision about where the older adult will go after they get out of the hospital. I also want to learn about how they work together to make the decision.

   You are being asked to participate in this study because you are working with a patient who is deciding about where they will go when they get out of the hospital. I will also be talking with your patient and their family member. I will ask them questions similar to the ones I am asking you.

   This research is being done because we know very little about how frail older adults and their families work with hospital staff to make this decision. Older adults often get out of the hospital very quickly, while they are still sick. If we can learn more about how frail older adults and their families work with hospital staff, then maybe we can prevent problems, like unexpected return to the hospital, or not enough help at home.

2. If you volunteer, you will take part in this study for 2 days until all the information is collected. About 60 people (20 older adults, 20 family members, and 20 health care team members) will take part in the study at Boone Hospital Center.

3. Taking part in this study is completely voluntary. Your employment at Boone Hospital Center will not be affected in any way by your decision to or not to participate. There are no risks to quitting the study.

   I may decide to take you out of this study if your patient can no longer participate because their health suddenly gets worse and they have to go to an intensive care unit for more than 24 hours or if they go home before the study is finished.

4. What is involved in the research?

To be in the study your patient must be close to the time when they will be deciding where to go when they get out of the hospital. This will most likely be within 48 hours of leaving the hospital. Your patient must also have a family member who is helping them to make decisions, who is also willing to be in the study.

I will be asking you to complete a simple questionnaire to help me understand more about you, such as your age, your gender, race, professional position held, and degrees. Next, I will ask you to look at cards that show how much participation you want when making decisions. Finally, I will be asking you a few questions about the discharge destination decision including any issues you may have had concerning the decision that was made. This part of the study should take no more than 45 minutes unless you have a lot to say to me when we are talking.

5. You will be told about any new information that might affect your willingness to continue to take part in this study.

6. What are the risks of the study?

There are few risks of being in the study. The simple act of talking about the discharge destination decision may bring to light some issues that were not previously considered in discharge planning. This may create some additional discharge planning work for you.

If you are concerned about any of the things that I have described to you, please let me know immediately. You can call me at 573-445-2354 or 573-815-8428.

7. Are there benefits to taking part in the study?

If you agree to be in this study, there may or may not be a direct benefit to you. We hope the information learned from this study will benefit other patients, families, and health care team members who are working together to make decisions about discharge from the hospital in the future. Other benefits may include having the opportunity to tell someone about your experiences with hospital discharge planning.

8. What other options are there?

If you decide not to take part in this study, it will in no way affect your employment at Boone Hospital Center. I am not interested in changing your patient’s decision about where to go after discharge, but I am interested in understanding more about how the decision was made.

9. What are the costs?

There is no cost to you for participating in the study.

You will not be paid for taking part in this study.

10. The investigator is a doctoral student at Sinclair School of Nursing-University of

Missouri and receives no payment for this study.

11. <u>What about confidentiality?</u>
    Information that you give me will be stored in my file and identified by a code number only. The code key connecting your name to specific information about you will be kept in a separate, secure location. Information contained in your records may not be given to anyone not connected with the study in a form that could identify you without your written consent, except as required by law.

    It is possible that your research record, including sensitive information and/or identifying information, may be inspected and/or copied by the Boone Hospital Center and University of Missouri Health Sciences Institutional Review Boards, federal or state government agencies, or hospital accrediting agencies, in the course of carrying out their duties. If your record is inspected or copied by the by any of these agencies, Boone Hospital Center and the University of Missouri will use reasonable efforts to protect your privacy and the confidentiality of your information.

    The results of this study may be published in a medical book, journal, or in research presentations for teaching purposes. However, your name or other identifying information will not be used in any publication or teaching materials without your specific permission.

12. <u>Additional concerns</u>
    If you are injured in any way as a result of taking part in this study, you may contact Lori Popejoy at 573.815.8428 or 573.445.2354. She will make every effort to address problems caused by the study. There are no funds for compensation set aside for research-related injuries. However, by signing this form, you do not give up any of your legal rights for compensation.

13. The procedures in this study may have risks, and it is not the policy of Boone Hospital Center to compensate for injury resulting from the study treatment or other procedures. The hospital has insurance coverage for injury caused by negligence. If you believe you have suffered injury as a result of your participation in this study, you may contact the Quality/Risk Management Coordinator, at (573) 815-3762.

14. <u>Questions</u>
    Please ask any questions you have about this research and ***Lori Popejoy*** will answer them. If you decide to volunteer and have questions later on during your participation, please feel free to ask them. Make sure that all your questions are answered to your satisfaction. If you have any questions or problems, please call Lori Popejoy at 573.815.8428 during the day or 573.445.2354 in the evening.

15. If you have questions about your rights as a research subject, you may contact the IRB chairman, David Brummett, MD, at (573) 815-8000.

16. In order to take part in this study, you will need to give your written consent. You may change your mind and withdraw your consent at any time.

I consent to participate in this study. My consent is given freely, and I have read and understand the explanation of my rights in the summary above. I am satisfied with the explanation of the study contained in the summary above, and I have had all of my questions answered to my satisfaction. I understand that I am not required to sign this form or participate in this study. I understand that I may withdraw my consent at any time.

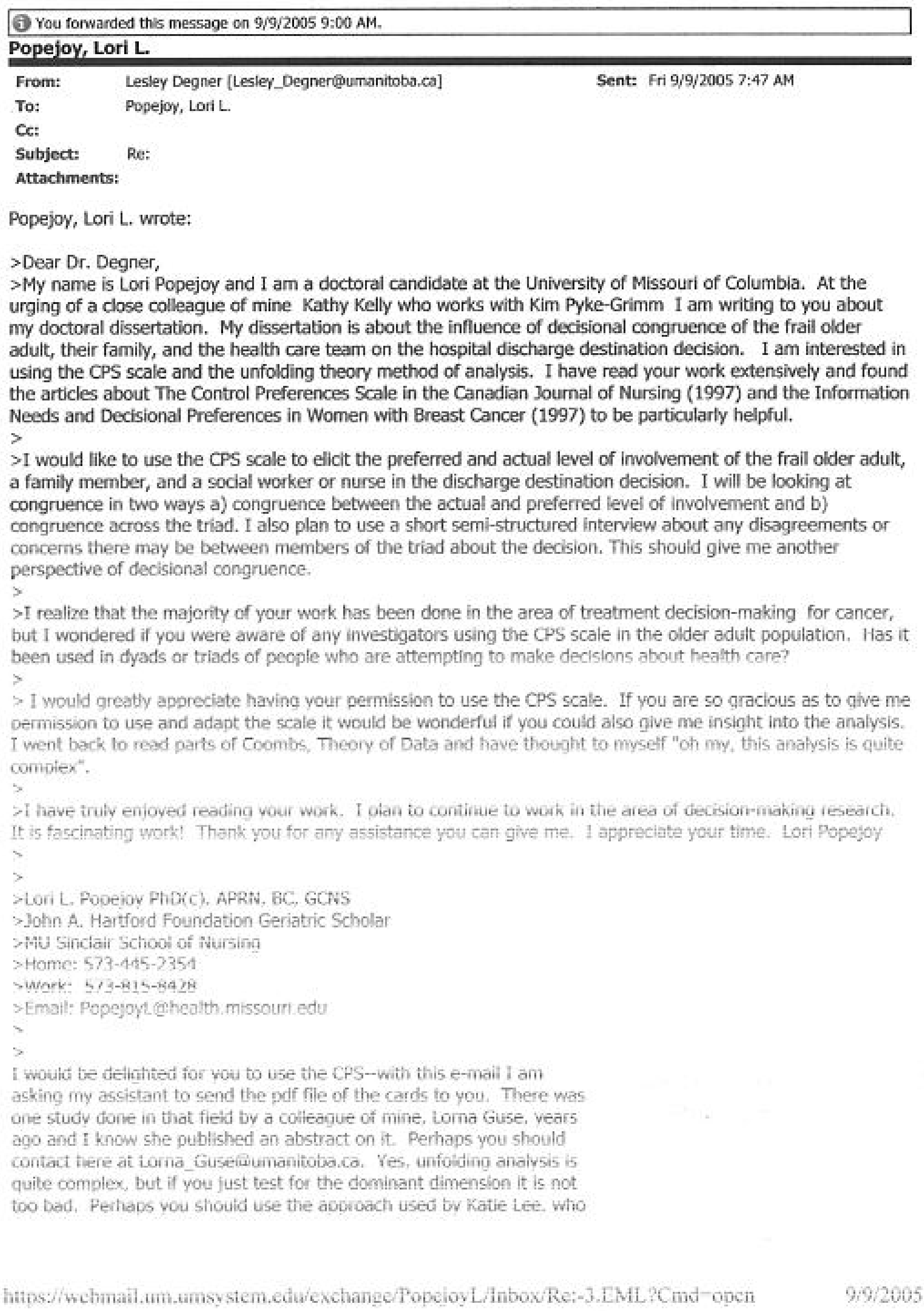
Patient	Date
Investigator	Date
Witness	Date

RESEARCH SUBJECT'S BILL OF RIGHTS

You have been asked to participate as a subject in a clinical research procedure. Before you decide whether you want to take part in research procedures, you have the right to:

1. To be informed of the nature and purpose of the research;
2. To be given an explanation of the procedure to be followed in the medical research, and any drug or device to be used;
3. To be given a description of any discomforts and risks reasonably to be expected from taking part in the research;
4. To be given an explanation of any benefits reasonably to be expected from your participation in the research, as applicable;
5. To be given a disclosure of any appropriate alternative treatments that might be helpful to you, and their relative risks and benefits;
6. To be informed of medical care available to you if complications or side effects should occur;
7. To be given an opportunity to ask any questions concerning the medical research and the procedures involved;
8. To be instructed that you may change your mind and withdraw your consent at any time and that you may stop taking part in the research without adversely affecting your future care or relationship with your doctor;
9. To be given a copy of the signed and dated written consent form; and
10. To be given the opportunity to decide to consent or not to consent to the research without any element of force, fraud, deceit, duress, coercion, or undue influence on your decision.

Appendix 15, Approval to Use CPS Instrument



You forwarded this message on 9/9/2005 9:00 AM.

Popejoy, Lori L.

From: Lesley Degner [Lesley_Degner@umanitoba.ca] **Sent:** Fri 9/9/2005 7:47 AM
To: Popejoy, Lori L.
Cc:
Subject: Re:
Attachments:

Popejoy, Lori L. wrote:

>Dear Dr. Degner,
>My name is Lori Popejoy and I am a doctoral candidate at the University of Missouri of Columbia. At the urging of a close colleague of mine Kathy Kelly who works with Kim Pyke-Grimm I am writing to you about my doctoral dissertation. My dissertation is about the influence of decisional congruence of the frail older adult, their family, and the health care team on the hospital discharge destination decision. I am interested in using the CPS scale and the unfolding theory method of analysis. I have read your work extensively and found the articles about The Control Preferences Scale in the Canadian Journal of Nursing (1997) and the Information Needs and Decisional Preferences in Women with Breast Cancer (1997) to be particularly helpful.
>
>I would like to use the CPS scale to elicit the preferred and actual level of involvement of the frail older adult, a family member, and a social worker or nurse in the discharge destination decision. I will be looking at congruence in two ways a) congruence between the actual and preferred level of involvement and b) congruence across the triad. I also plan to use a short semi-structured interview about any disagreements or concerns there may be between members of the triad about the decision. This should give me another perspective of decisional congruence.
>
>I realize that the majority of your work has been done in the area of treatment decision-making for cancer, but I wondered if you were aware of any investigators using the CPS scale in the older adult population. Has it been used in dyads or triads of people who are attempting to make decisions about health care?
>
> I would greatly appreciate having your permission to use the CPS scale. If you are so gracious as to give me permission to use and adapt the scale it would be wonderful if you could also give me insight into the analysis. I went back to read parts of Coombs, Theory of Data and have thought to myself "oh my, this analysis is quite complex".
>
>I have truly enjoyed reading your work. I plan to continue to work in the area of decision-making research. It is fascinating work! Thank you for any assistance you can give me. I appreciate your time. Lori Popejoy
>
>
>Lori L. Popejoy PhD(c), APRN, BC, GCNS
>John A. Hartford Foundation Geriatric Scholar
>MU Sinclair School of Nursing
>Home: 573-445-2354
>Work: 573-815-8428
>Email: PopejoyL@health.missouri.edu
>
>

I would be delighted for you to use the CPS--with this e-mail I am asking my assistant to send the pdf file of the cards to you. There was one study done in that field by a colleague of mine, Lorna Guse, years ago and I know she published an abstract on it. Perhaps you should contact here at Lorna_Guse@umanitoba.ca. Yes, unfolding analysis is quite complex, but if you just test for the dominant dimension it is not too bad. Perhaps you should use the approach used by Katie Lee, who

https://webmail.um.umsystem.edu/exchange/PopejoyL/Inbox/Re:-3.EML?Cmd=open 9/9/2005 graduated with her Ph.D. from Yale--I am sure you can order a copy of her thesis. Her data analysis sections are very good. Lesley Degner

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Vita

Lori Lea Popejoy was born April 27, 1959, in Kearney, Nebraska. After attending public schools in Kearney Nebraska, she received her Diploma in Nursing from Bryan Memorial Hospital School of Nursing (1980) and became a registered nurse. She moved to Columbia, Missouri in 1982 where she worked as a practicing nurse in critical care at Boone Hospital Center. She remained at Boone Hospital Center for over 10 years serving as Director of Medical Intensive Care and Nursing Practice Specialist. She received the following degrees: Bachelor of Science of Nursing from the University of Missouri-Columbia (1993); Master of Science of Nursing (1996); Doctor of Philosophy (2007). After receiving her BSN she worked as a clinical expert and study coordinator on multiple long-term-care research studies at the MU School of Nursing and Family Community Medicine. After beginning her doctoral coursework, she was awarded a prestigious predoctoral scholarship by the John A. Hartford Foundation, Building Academic Nursing Capacity. She is married to Sidney R. Popejoy of Columbia, Missouri; they have two children, Adam Popejoy and Katherine Popejoy.