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Care Coordination for Cognitively Impaired Older Adults and Their Caregivers

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Abstract

Dementia and delirium, the most common causes of cognitive impairment (CI) among hospitalized older adults, are associated with higher mortality rates, increased morbidity and higher health care costs. A growing body of science suggests that these older adults and their caregivers are particularly vulnerable to systems of care that either do not recognize or meet their needs. The consequences can be devastating for these older adults and add to the burden of hospital staff and caregivers, especially during the transition from hospital to home. Unfortunately, little evidence exists to guide optimal care of this patient group. Available research findings suggest that hospitalized cognitively impaired elders may benefit from interventions aimed at improving care management of both CI and co-morbid conditions but the exact nature and intensity of interventions needed are not known. This article will explore the need for improved transitional care for this vulnerable population and their caregivers.

Keywords

dementia; delirium; transitional care; advanced practice nurses

Background

For more than 15 years, our multidisciplinary research team has been testing evidence-based clinical interventions guided by the Quality Cost Model of APN Transitional Care (hereafter referred to as the APN Care Model). These interventions have been designed to improve the quality of care and outcomes of high risk cognitively intact older adults as they make the difficult transition from hospital to home. Findings from three NIH-funded randomized control trials (RCTs) have consistently demonstrated improved quality and reductions in hospital readmissions and health care costs among intervention patients compared to control patients receiving standard care (Naylor et al., 1994; Naylor et al., 1999; Naylor et al., 2004). Recently, our team has begun to extend application of the APN Care Model to other high risk patient groups. With the support of the Alzheimer's Association, we have conducted pilot studies that have yielded important information about the unique health issues faced by cognitively impaired older adults and their caregivers during transitions from hospitals to home and

suggested the value of interventions designed specifically to meet their needs (Naylor, Stephens, Bowles, & Bixby, 2005). Currently, with the support of the National Institute of Aging and Marian S. Ware Alzheimer's Program, our team is testing a range of interventions designed to enhance the care management of elders with cognitive impairment (CI) and their caregivers throughout episodes of acute illnesses. The purpose of this paper is to examine the need for enhanced transitional care among hospitalized cognitively impaired older adults and their caregivers and to describe the evolution of a major research initiative designed to inform critically needed changes in clinical practices.

Significance

Dementia and delirium are the two most common cognitive disorders affecting older adults and often coexist within this population. Dementia is a neurodegenerative disease characterized by memory impairment, other cognitive deficits and associated behavioral disorders that result in a progressive loss of autonomy in common daily activities (Caltagirone, Perri, Carlesimo, & Fadda, 2001). In contrast, delirium, an acute disruption in cognition characterized by disturbances in consciousness, orientation, memory, thought, perception and behavior, is a multi-factorial syndrome resulting from the interaction of patient vulnerability and hospital related insults (Inouye, 1994). At the time of hospital admission, between 15% and 20% of older adults meet the criteria for delirium-prevalent cases (Francis, Martin, & Kapoor, 1990; Cameron, Thomas, Mulvihill, & Bronheim, 1987; Erkinjuntti, Wikstrom, Palo, & Autio, 1986; S. Levkoff, Cleary, Liptzin, & Evans, 1991; Rockwood, 1989; Schor et al., 1992). Most studies report a subsequent incidence during hospitalization of 5% to 10% (Francis et al., 1990; Cameron et al., 1987; Erkinjuntti et al., 1986; Levkoff et al., 1991; Rockwood, 1989; Schor et al., 1992; Inouye, 1998). The prevalence of dementia among persons discharged from acute care hospitals ranges from 4% to 27% (Fick, Agostini, & Inouye, 2002). Prevalence rates for both conditions are expected to increase as the population ages (Caltagirone et al., 2001). Recent advances in science support a strong relationship between these cognitive disorders. Between one-quarter to three quarters of patients with delirium have dementia (Cole, 2004; Fick et al., 2002) and the presence of dementia increases the risk of delirium by fivefold (Elie, Cole, Primeau, & Bellavance, 1998). Therefore assessment of both delirium and dementia should be part of a comprehensive assessment at hospital admission and throughout the hospital stay.

Current evidence reveals a higher level of comorbidity among patients with CI than among cognitively intact patients (Fields, MacKenzie, Charlson, & Sax, 1986; Gutterman, Markowitz, Lewis, & Fillit, 1999; Hill et al., 2002; Lyketsos, Sheppard, & Rabins, 2000; McCormick et al., 2001). Collectively, CI and chronic medical illnesses result in greater morbidity, increased preventable hospitalizations and poorer survival (Feil, Marmon, & Unutzer, 2003; Zuccala et al., 2003). Investigators hypothesize that medical conditions may negatively impact cognition and neurodegeneration (Bynum et al., 2004; Doraiswamy, Leon, Cummings, Marin, & Neumann, 2002; Feil et al., 2003; McCormick et al., 1994; Zuccala et al., 2003). Conversely, CI among elders with other comorbid conditions may lead to inaccurate symptom reporting, delayed or inadequate treatment of the comorbid conditions and nonadherence with prescribed therapies (Doraiswamy et al., 2002; McCormick et al., 1994; Sloan, Trogon, Curtis, & Schulman, 2004; Sullivan-Marx, 1994). When CI co-exists with depression (approximately 20% of cases), adherence with prescribed therapies, and thus outcomes, are especially poor (Feil et al., 2003).

Despite its clinical importance, CI is often not detected or it is misdiagnosed (Francis, 1992; Francis & Kapoor, 1992; Gustafson et al., 1991; Inouye, 1994; Kakuma et al., 2003; Levkoff, Besdine, & Wetle, 1986; Rothschild, Bates, & Leape, 2000; Schor et al., 1992; Naylor et al., 2005). Consequently, CI often triggers a cascade of undesirable adverse clinical events (ACEs)

such as deconditioning, falls, malnutrition, and incontinence during hospitalization and immediately following discharge (Fick & Foreman, 2000; Greenwald et al., 1989; Inouye, 1994; Muehrer, 2002; Rothschild et al., 2000). Even when assessed, CI among hospitalized elders is poorly managed. Management of symptoms (Burgener & Twigg, 2002; Wing, Phelan, & Tate, 2002), especially pain (Given & Given, 1991; Rothschild et al., 2000), is compromised and disruptive, unsafe behaviors are common and often untreated (Burgener & Twigg, 2002; Sullivan-Marx, 1994; Wing et al., 2002). Thus, delirium and dementia appear to be independently associated with significant increases in functional disability, numbers of hospitalizations, lengths of hospital stay, rates of admissions to nursing homes, rates of death and health care costs (Britton & Russell, 2001; Fick & Foreman, 2000; Francis et al., 1990; Inouye, 1994; Inouye, Rushing, Foreman, Palmer, & Pompei, 1998; Inouye, Schlesinger, & Lydon, 1999; Levkoff et al., 1992; Marcantonio, Flacker, Michaels, & Resnick, 2000; O'Keeffe & Lavan, 1997). In 1999, increased hospital admissions and longer lengths of stay accounted for greater than 50% of adjusted costs with admissions for preventable hospitalization, more than two times greater than for non-demented patients (Bynum et al., 2004). Delirium complicates stays accounted for an additional \$6 billion (in 2000 U.S. dollars) of total Medicare expenditures (The Hospital Elder Life Program, 2003).

Most of the interventions reported to date have evaluated the effectiveness of early detection and management of causal factors of delirium. Study findings suggest that such approaches are modestly effective in preventing delirium among surgical patients (Gustafson et al., 1991; Inouye, Bogardus et al., 1999; Marcantonio, Flacker, Wright, & Resnick, 2001; Milisen et al., 2001; Wanich, Sullivan-Marx, Gottlieb, & Johnson, 1992). The few successful interventions targeting the management of delirium or dementia included training clinicians to improve the recognition and management of CI, using evidence-based clinical guidelines, and tailoring interventions to meet individualized needs (Inouye, Bogardus et al., 1999; Rizzo et al., 2001; Marcantonio et al., 2001; Young & George, 2003). Despite the fact that delirium can persist for months following discharge and both cognitive disorders continue to complicate the care of these patients following discharge, none of the reported interventions spanned hospital to home (Bogardus et al., 2003).

Often, it is left to family caregivers to meet the complex needs of cognitively impaired elders following hospital discharge. Study findings suggest that their lack of knowledge and skills contribute to poor patient outcomes (Kelley, Buckwalter, & Maas, 1999; Mui, 1995; Zarit, Reever, & Bach-Peterson, 1980), increased caregiver burden (Charlesworth, Riordan, & Sthepstone, 2000; Nolan, Grant, & Keady, 1996) and depression (Poulshock & Deimling, 1984). A meta-analysis of 30 studies testing psychosocial interventions for caregivers of people with dementia revealed that interventions that were more intensive, adapted to meet individualized needs, and targeted both patients and their caregivers were more successful in reducing caregiver burden, increasing their knowledge and skills, enhancing their satisfaction and preventing or delaying elders' institutionalization (Brodsky, Green, & Koschera, 2003).

In summary, CI is a major health problem complicating the care of increasing numbers of older adults hospitalized for an acute medical or surgical condition. Dementia and delirium, the most common causes of CI among these elders, are associated with higher mortality rates, increased morbidity and higher health care costs. A growing body of science suggests that these patients and their caregivers are particularly vulnerable to systems of care that either do not recognize or are unable to meet their needs. The consequences are devastating for the patients and their caregivers and add tremendous burden to hospital staffs coping with shortages of nurses. Thus, it is not surprising that the Institute of Medicine (IOM) identified improved care coordination of this patient group as a national priority for action (Institute of Medicine, 2003).

Unfortunately, little evidence is available to guide optimal care of this patient group or to address the unique needs of their caregivers. Collectively, available evidence suggests that

these patients may benefit from interventions aimed at improving management of CI, comorbid conditions or both but the exact nature and intensity of interventions needed to effectively and efficiently improve their outcomes and those of their caregivers is not known.

Extending the APN Care Model to Cognitively Impaired Hospitalized Elders: Building on the Science

Building on this base of science we designed a study to determine how large a problem CI was among elders hospitalized for common medical and surgical conditions. This pilot work had two phases, the first phase (Pilot Study I) consisted of determining the presence of CI among hospitalized older adults and the second phase (Pilot Study II) consisted of interviewing a small subset of older adults and caregivers to identify their needs during the transitions from hospitals to home. Findings from these studies informed the design of a large scale RCT.

Pilot Study I – Defining the problem

To assess the extent of impairment in this population, older adults hospitalized from home were sequentially screened for the presence of CI at three urban hospitals in the Philadelphia area. Hospitalized elders were eligible if they were 70 years old; English speaking; admitted for a common cardiovascular, respiratory, orthopedic or endocrine medical or surgical event; and had a primary caregiver, defined as a spouse, family member, partner or friend, who provided assistance with care. After meeting inclusion criteria subjects were screened for CI using the Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975) (scores of <24 on this 30 item scale were considered impaired), Brief Dementia Severity Rating Scale (BDSRS) (Clark & Ewbank, 1996), and the Confusion Assessment Method (CAM) (Inouye et al., 1990) (scored as the presence or absence of delirium). A detailed description of the screening process is presented elsewhere (Naylor et al., 2005).

Findings—Of the 145 hospitalized elders screened in this study, 35% (51/145) had some form of CI (Naylor et al., 2005). Among the group of elders with CI, 65% met the criteria for CI based solely on the screening instruments (i.e., no diagnoses of dementia or delirium noted in the chart), 18% had a preexisting diagnosis of dementia, and 18% had a preexisting diagnosis of delirium. In-depth interviews with a sub-sample of these elders and their caregivers (5/51) revealed numerous unmet needs including managing and negotiating care with multiple providers, managing illness (e.g., identifying and managing physical and psychological symptoms, adhering with prescribed therapies, managing problem behaviors, and lack of awareness of community resources), and psychosocial support and coping (e.g., depression among patients and burden, depression, isolation and fear among caregivers) (Naylor et al., 2005).

Pilot Study II – testing the feasibility of the APN Care Model

Using the results from Pilot Study I (Naylor et al., 2005) and prior transitional care work with cognitively intact elders (Naylor et al., 1999; Naylor et al., 2004; Naylor et al., 1994) Pilot Study II was designed to: 1) test the effectiveness of the APN Care Model specifically designed for the needs of cognitively impaired adults and their caregivers; 2) determine which elements and interventions are most beneficial to cognitively impaired older adults and their caregivers during hospitalization and post-discharge periods; and, 3) design a large scale follow-up study to improve outcomes for hospitalized cognitively impaired older adults and caregivers.

Screening criteria and enrollment procedures were the same as in Pilot Study I. The sample of convenience consisted of 11 patient-caregiver dyads. All approached agreed to participate, one died during the index hospitalization. During each data collection visit (baseline, 2-, 6-, 12-weeks) several standardized instruments interviewer administered. In addition to the three CI

screening scales – MMSE, BDSRS, and CAM –, data were collected on bothersome symptoms (Symptom Bother Scale) (Heidrich & Ryff, 1993), depression (Geriatric Depression Scale, GDS, and Center for Epidemiologic Studies Depression scale, CES-D) (Brink et al., 1982; Radloff, 1977), quality of life, assistance needed for activities of daily living, support provided by the caregiver, rehospitalizations, overall mental and physical health ratings, caregiver satisfaction, and patient behaviors.

Intervention—The intervention was specifically designed to make use of existing successful strategies shown to positively influence patient and caregiver outcomes. Patient-caregiver dyads received a six week APN provided transitional care intervention aimed at identifying and meeting the unique needs of the cognitively impaired older adult and their caregiver using the APN Care Model as a framework. The APNs were clinical nurse specialists or nurse practitioners with a Master of Science in Nursing specializing in adult health, acute care or gerontology with a minimum of 5 years experience post-Masters in the care of an elderly population. The specific nurses in this pilot had extensive experience with the application of the APN Care Model from previous work on the RCTs. The APNs acted as clinician and collaborator in acute care, rehabilitation or home settings performing a comprehensive physical, emotional, mental and social assessment and developing a unique plan of care working with the older adult, caregiver, and collaborating health care professionals to meet mutually agreed and attainable goals.

These APNs provided the vital link from one level of care to the home and in the home setting. They implemented a comprehensive plan of care through patient and caregiver education regarding diagnosis, symptom management, accessing needed services, equipment, and health care professionals. The nurse experts collaborated with primary care and specialist practitioners as well as other health care professionals to address needs and problems key to meeting goals and refining the plan of care to address changing patient and caregiver needs. The APNs focused on care coordination, advocacy, and education through home visits as well as phone contact to the older adult and provided demonstration of effective advocacy behavior for caregivers and other patient support.

Results

Of the enrolled older adults, 5 were Caucasian and 5 African American; they ranged in age from 72–89 (mean 82.1 ± 6.7 years) with a baseline mean MMSE score of 18 (± 3.0 ; range 13–23). Caregivers were all female, aged 43–85 (mean 62); length of time in the caregiver role ranged from 1 month to 10.2 years. Four were Caucasian, 5 African American and 1 Native American. These women were primarily spouses or children of the care recipient (70%). Despite the challenges faced, they reported high self rated overall health scores and little desire to explore nursing home options. Sixty percent of the caregivers used no support services, yet all performed at least four care giving tasks; 30% percent reported they had no one to help them and were also the primary caregiver to another person. When assessed for burden, 30% felt they were “missing out on life,” 40% wished they could escape from their situation, 40% felt emotionally drained and 30% thought that “life would be different.” Depression scores using the CES-D indicated high levels of depressive symptoms at baseline (Mean = 16 ± 7 ; range 12–34). The most common behavioral problems reported by caregivers were auditory hallucinations and day/night disturbances.

Case Studies

The following two case studies illustrate the application of the APN Care Model and the challenging situations and complex management encountered while caring for older adults with CI and their caregivers.

Case Study #1

Complexity of Care—On enrollment, Mr. S. had 10 co-morbid conditions requiring active treatment. These included: heart failure (HF) with an ejection fraction of < 15% treated with deployment of a biventricular pacemaker, coronary artery disease (CAD) resulting in two prior coronary artery bypass grafting procedures and an angioplasty; ventricular tachycardia necessitating placement of an automatic internal cardioverter defibrillator (AICD); chronic renal insufficiency; anemia; benign prostate hypertrophy; depression treated with Paxil; dementia treated with Aricept; and bilateral cataract removal. He was prescribed 12 daily medications. His MMSE score was 16 at enrollment. During his inpatient episode Mr. S exhibited signs of hospital acquired delirium manifested by sleep disturbances, aggressive behavior towards staff and refusal of most basic care. Mr. S also reported being greatly bothered by a number of symptoms including aching, feeling tired and weak, pain, shortness of breath, incontinence, and concentration and memory problems.

Mr. S's available resources were his two daughters and wife. One daughter lived with the patient but was physically not available to assist, though she frequently told Mrs. S, her mother, what to do. This often made Mrs. S. resentful and not willing to give up "control" of care. Additionally, Mr. S. had a large circle of friends who called frequently but were not physically able to assist. The patient had friends at a senior center and, when well enough, visited on a weekly basis but was actively discouraged from attending by his wife. The living areas of the home were on one floor with limited steps at entrances. Mr. S changed to a new primary care provider (PCP) during hospitalization. In addition he had been seen as an outpatient by a nephrologist and three cardiologists.

Clinical Priorities—Mr. S had progressive congestive HF and required vigilant home monitoring. He did not tolerate the preferred heart failure treatments having an intolerance to angiotension converting enzyme (ACE) inhibitor and an "allergy" (rash) to Carvedilol. He had repeated hospitalizations for exacerbation of HF responsive to intravenous (IV) Milrinone. He was diagnosed with multi-infarct dementia by his former PCP after reported memory decline over the prior three years. Approximately six months prior to enrollment in this pilot he began treatment with Aricept. Mr. S's wife stated she saw improvement but his daughter noted little improvement but did indicate there was no continued memory decline. At discharge his new PCP was unfamiliar with the prior CI treatment and discontinued the Aricept Mr. S had been receiving, believing it was prescribed to treat the hospital acquired delirium not the underlying dementia. The new PCP believed the delirium would clear slowly on return to home and improve with congestive HF management.

Barriers—Barriers to implementation of the APN Care Model are multifaceted but typically issues are related to one or more of the following: the elder, the caregiver, the health system or communication. In this case study all four areas acted as barriers to implementation and needed to be addressed by the APN in order to achieve minimal success. Mr. S's diagnosis of depression, dementia and delirium in the hospital resulted in limitations in recall, at times even not recognizing the APN or PCP, which affected the ability to provide meaningful patient education or an active role for the older adult in needs assessment and goal formation.

Conflicting goals and perceptions of the caregivers, their competing needs and grief over the potential loss of their loved one provided significant barriers for the APN. Mrs. S was depressed over her husband's rapid physical and mental decline over the past few weeks, stating she *"thought her life would be different at this point in time."* She was also highly anxious regarding care giving responsibilities frequently stating, *"I'm going to kill him if I don't do it right"* and *"My daughter makes me feel so guilty."* Mr. S's daughter was in denial of CI although acknowledging that her father could no longer tell time. The caregivers had been in family

counseling to address mother-daughter relationship issues for 2 years. They stopped going to weekly sessions when Mr. S was hospitalized. The APN discussed the need to resume the family counseling and encouraged both to continue to seek counseling which they did. The caregivers were not physically or emotionally able to manage the home IV Milrinone which limited the cardiologist's treatment plan to optimizing oral HF medications.

Health systems issues impacted the implementation of the plan of care. The prior diagnosis of dementia made by a former PCP was not addressed by Mr. S's new provider and treatment with Aricept was discontinued. Treatment of his hospital acquired delirium was not addressed as the new PCP and family believed this would clear with Mr. S's return to a familiar environment and better management of HF. Additionally, the multiple specialist physicians involved in the case made contradictory recommendations regarding dementia treatment. One physician refused to continue Aricept as he thought there was a potential interaction with Coumadin and a potential heightened bleeding risk, another physician said the memory impairment, common in individuals with multiple CABG surgeries, was expected and not necessarily needing treatment while another physician weighed in that since the patient did not have Alzheimer's Disease, his antidepressant could be discontinued. This resulted in Mr. S exhibiting increased aggression and anger toward his family after discharge to home. The APN requested restarting the antidepressant with slow resolution of untoward behavior. Additionally, the APN sought referral to a memory disorder clinic. Given the long waiting list at a memory disorder clinic, referral to a geropsychiatric nurse practitioner was also sought and her insights were helpful in reinforcing the APN's recommendations and increasing physician-APN collaboration.

Facilitators—Facilitators to implementation of APN Care Model and attainment of patient and caregiver goals included: sufficient income, insurance and medication coverage; access to specialty and primary care; involvement of the area Alzheimer's Association; and positive supports from the visiting nurse association. Mr. S's MMSE scores improved over time from 16 to 21. In addition, Mr. S reported no longer being bothered by symptoms such as aching, pain, incontinence, and concentration problems. Despite these positives, the Mr. S's wife never felt comfortable with her care giving ability and Mr. S was admitted to a long term care facility after the sixth week of intervention.

Case Study #2

Complexity of Care—Mrs. J is an 86 year-old admitted to an outlying hospital for chest pain and shortness of breath. After initial stabilization she was transferred on day three of her hospitalization to a teaching hospital for further evaluation of her symptoms. After this transfer Mrs. J began to exhibit delirium – easy confusion, sleep disturbances, aggressive nighttime behaviors – without chronic mental status change which limited retention and ability to conduct necessary patient education. On enrollment, Mrs. J. had four co-morbid conditions: CAD requiring cardiac catheterization and placement of an intracoronary stent; arthritis; cataracts; and hypercholesterolemia. Her baseline MMSE score was 20. Mrs. J also reported being greatly bothered by feeling tired and achy.

Mrs. J lived alone and was her own primary caregiver. She was prescribed three medications on discharge. One medication was for short term use given the stent placement. The other medications were all new to Mrs. J as she had not previously taken daily standing medications. Resources available to Mrs. J included a niece who lived out of state (> 4 hours travel) and a friend who lived near Mrs. J identified as helper and first contact. Mrs. J had not seen a doctor for checkups for many years and had many unmet preventative care needs. She was referred upon discharge to the PCP who had admitted her as well as the cardiologist who had seen her while hospitalized. She also identified a need for follow-up with an ophthalmologist to

determine the status of her cataracts. Clinical priorities on discharge were monitoring of her liver enzymes which were elevated during hospitalization; diet education; development of an exercise program; clinical follow-up; medication education; and monitoring the recovery of her cognition.

Barriers—The primary barrier for Mrs. J was assuring safety during the transition to home on discharge and establishing a plan to monitor Mrs. J overnight during the first days after discharge. Given travel distances Mrs. J's niece could not actively participate in the provision of care. Mrs. J was able to identify friends who would be willing to assume this role for the short-term. Health system barriers included new providers; hospital acquired delirium with no medical or nursing notes to indicate this was assessed or being treated; lack of physical therapy consult despite a noted gait disturbance; and inadequate discharge planning assessment of needs related to transportation and clothing.

Facilitators—During the hospitalization nurses and physicians collaborated with the APN to assure transitional needs were met and safety at discharge was assured. This was accomplished through delay by one day, at the APNs suggestion, of Mrs. J's discharge home, identification of local caregivers able to spend the night at Mrs. J's home and assessment of Mrs. J's understanding of her Cland plan of care. The APN was able to visit Mrs. J within hours of her discharge and provide an in-depth assessment of her living conditions and troubleshoot potential problems. The APN was also able to work with the caregiver to educate her as to signs and symptoms to report and re-orientation strategies. The APN was flexible in scheduling visits to provide maximum support and assessment of the continuing delirium during the first two weeks of intervention.

In addition to these assets, Mrs. J had a prescription plan with minimal co-pay which was not a financial hardship. Her living arrangement was ideal, a first floor apartment with grab bars in bathroom, good lighting, laundry facilities on the same level and neighbors who checked on her daily. A friend assisted with laundry and visited daily after initially spending several nights at Mrs. J's home. Friends at the senior center were supportive through phone calls and visits. Another friend provided cleaning, transportation and food delivery. Importantly, Mrs. J trusted the APN, asked for help appropriately and followed through on directions about activities, medications, and diet. Though not physically present her niece seemed genuinely concerned via phone and asked appropriate questions. Through the intervention of the APN Mrs. J was able to return home after hospitalization avoiding short-term skilled nursing placement. During the course of the intervention Mrs. J's MMSE improved from 20 at enrollment to 28 at the 12 week follow up. Mrs. J also reported that the symptoms of feeling tired or achy no longer bothered her.

Overall improvements among all the older adults in the pilot study—

Improvements in mean MMSE scores after six weeks of APN intervention (mean MMSE = 20.5) persisting to 12 weeks (mean MMSE = 22) post-enrollment were noted with most improvement in those older adults with a higher baseline MMSE. The nature and severity of symptom complaints were significantly reduced over the 12 week period (baseline Symptom Bother Scale – mean = 12.9 ± 7.4 , range 3–22; 12 week follow up: mean = 8 ± 3.9 , range 4–13) with particular improvements noted in management of pain and mobility.

Summary of Pilot Experience—Based on prior experience with similar high risk elders, the APNs provided valuable input related to the design and implementation of the pilot study intervention. For example, the APNs successfully identified nursing and medical champions at the sites who helped them influence the care of these older adults while hospitalized. In addition, they suggested the need for increased awareness by hospital staff about geropsychiatric resources for cognitively impaired patients and their caregivers. APNs reported

little difficulty in tailoring the intervention to caregivers. All caregivers reported that they valued the involvement of the APN during the episode of illness. Finally, case studies completed by APNs highlighted the critical importance of interventions. Among nine older adults in the pilot, APNs prevented a serious medication error for one older adult and delayed discharges until essential follow-up care could be provided in the home for two other older adults, neither of whom had been identified by medical or nursing staff as having evidence of CI.

These pilot study findings coupled with the needs assessment revealed a high rate of unrecognized CI among hospitalized older adults and highlighted the unique needs and profound challenges facing elders and their caregivers as they adapt to a serious illness complicated by multiple comorbid conditions and CI. Improvements in mean MMSE scores at 12 week post-enrollment are likely the result of improvements or resolution of delirium. Findings informed the design of the intervention protocol, the APN orientation and training program, resource projections for the proposed study and modifications in data collection instruments.

Designing a Research Study to Address the Problem

With funding from the National Institute on Aging and the Marian S. Ware Alzheimer's Program we have designed an intervention study titled, "Hospital to Home: Cognitively Impaired Elders/Caregivers", to meet special needs of hospitalized elders with CI due to delirium, dementia or both. The interventions being tested in our current RCT were designed after synthesizing the published evidence and our own pilot findings. Our current work includes the strategies associated with positive results in the detection and management of CI and management of complex co-existing medication conditions during an acute episode of illness (Table 1).

Guided by Roy's Adaptation Model (Roy, 1976), a body of research in care management of cognitively intact high risk elders (Naylor et al., 1994; Naylor et al., 1999; Naylor et al., 2004), our pilot study findings (Naylor et al., 2005) and other empirical evidence, we developed a research study to test different nurse models of care for cognitively impaired elders and their caregivers. The different models being tested are:

1. *Augmented Standard Care (ASC)* - Standard hospital and home care (if referred). Older adults receive an assessment for CI during the hospitalization through the use of standardized instruments; including a brief investigator developed 6-item orientation screen, the CLOX (Royall, Cordes, & Polk, 1998) and the Confusion Assessment Method (CAM) (Inouye et al., 1990). Immediate feedback from these screens is provided to patients' primary nurses, attending physicians and discharge planners is provided in the medical record by the subject screeners in the form of a note entered into the patient's medical record;
2. *Resource Nurse Care (RNC)* – Standard hospital and home care (if referred) plus early identification of CI during the older adult's hospitalization as is provided in ASC. In addition, these patients' hospital care will be reviewed by RNs trained in the use of expert clinical guidelines developed to enhance the care management of hospitalized cognitively impaired elders and to facilitate their transition from hospital to home; or,
3. *Advanced Practice Nurse Care (APNC)* – Standard hospital care, early identification of CI during the older adult's hospitalization, plus transitional (hospital to home) care substituting for standard home care and provided by masters prepared nurse specialists with advanced training in the management of cognitively impaired older adults using an evidence-based protocol designed specifically for this patient group and their

caregivers. The APN is to be available by phone from 8:00AM–8:00PM Monday to Friday and 8:00AM – 12:00PM on weekends to provide support for the older adult and family members as needed. For each older adult an individual plan is developed for care needs outside of these hours. Additionally, the APN has the flexibility to schedule visits at any time to best meet the needs of the older adult and caregiver.

To avoid cross contamination within sites each model of care will be tested at a different site. Then, we will compare across the three hospital sites the effects on health outcomes and costs of the interventions. Upon completion of this first part of the study, all three sites will enroll subjects and provide APNC. In the second part of the study, we will seek to confirm initial findings by comparing within each site and over time, the health and cost outcomes from patients treated with either ASC or RNC (both relatively lower intensity interventions) with the outcomes of patients at the same site observed after switching to APNC (a high intensity intervention). Outcome data for each part of the study will be collected at multiple intervals and extend through six months post-index hospital discharge. Findings have the potential to inform improved care management of these older adults and their caregivers, an IOM priority for national action (Institute of Medicine, 2003).

Conclusion

Cognitive impairment adds substantial complexity to care needs for older adults and strain on caregivers attempting to cope with these elders. The risk for adverse events, such as medication errors, increases with cognitive impairment. The current care system in the United States is inadequate to address needs of older adults with CI. This study has been substantially informed by our team's program of research conducted over the last 18 years and aimed at enhancing care coordination (Bowles, Foust, & Naylor, 2003; Bowles, Naylor, & Foust, 2002; Bowles, 2000; Naylor, 2000, 2002; Naylor, Bowles, & Broton, 2000; Naylor et al., 1999; Naylor et al., 2004; Naylor et al., 2005) and effective collaboration among physicians, nurses and other providers and communication with patients and their caregivers during critical transitions in care. Compared to standard care, findings from this body of research have consistently demonstrated the benefits of comprehensive APN-directed care in improving health outcomes and decreasing health care costs among high-risk cognitively intact elders making the difficult transition from hospital to home. Noteworthy are recent findings demonstrating the benefit of APN care on both the primary illness and comorbid conditions (Naylor et al., 2004). The need now is to apply this body of research to improving transitions in care for the growing population of cognitively impaired older adults and their caregivers.

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Table 1

Strategies integrated into the current RCT interventions to meet the special needs of hospitalized elders with cognitive impairment (CI) due to delirium, dementia or both.

Strategies:

- Better screening and early detection of both delirium and dementia
- Prevention of adverse clinical events such as falls, drug interactions, Incontinence
- Prevention of delirium
- Early diagnosis of delirium
- Measurement of depression
- Multi dimensional intervention (education, support, reorientation)
- Medication reviews
- Use of protocols and guidelines with hospital follow up and including both patients and their caregivers
- Tailoring interventions to meet the needs of the patients and caregivers
- Focus on recognition and management of CI, acute illness, and comorbid conditions