Feasibility of Family Participation in a Delirium Prevention Program for the Older Hospitalized Adult

Deborah Rosenbloom-Brunton

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FEASIBILITY OF FAMILY PARTICIPATION IN A DELIRIUM PREVENTION PROGRAM FOR THE OLDER HOSPITALIZED ADULT

A Dissertation Presented

by

DEBORAH ROSENBLOOM-BRUNTON

Submitted to the Graduate School of the University of Massachusetts Amherst in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

MAY 2009

Graduate Program in Nursing
FEASIBILITY OF FAMILY PARTICIPATION IN A DELIRIUM PREVENTION PROGRAM
FOR THE OLDER HOSPITALIZED ADULT

A Dissertation Presented
By
DEBORAH ROSENBLOOM-BRUNTON

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Cynthia Jacelon, Member

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Jean Swinney
Dean, Nursing
DEDICATION

To my patient and loving husband, son, and parents who never fail to believe in me.
ACKNOWLEDGEMENTS

I would like to thank my advisor, Elizabeth Henneman, for her thoughtful and patient guidance and support. I would also like to extend my gratitude to the members of my committee, Carol Bigelow, Karen Helfer, and Cynthia Jacelon, for their insightful comments and challenges to broaden my thinking. Together their friendship and selfless contribution to my professional development have been invaluable and will forever be appreciated.

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I want to thank my research assistants, Rehn Hitschler and Crystal Therrien, who volunteered their participation in this project.

A special thank you to all of those whose support, friendship, and encouragement helped me to maintain my focus and passion for completing this project.
ABSTRACT

FEASIBILITY OF FAMILY PARTICIPATION IN A DELIRIUM PREVENTION PROGRAM

FOR THE OLDER HOSPITALIZED ADULT

MAY 2009

DEBORAH ROSENBLOOM-BRUNTON, B. A., SIMMONS COLLEGE

M. S., MGH INSTITUTE OF HEALTH PROFESSIONS

Ph.D., UNIVERSITY OF MASSACHUSETTS AMHERST

Directed by: Professor Elizabeth A. Henneman

OBJECTIVE: To examine the feasibility of family participation in a nurse-supported, multicomponent intervention program for delirium prevention in the older hospitalized adult.

BACKGROUND: Delirium is the leading complication of hospitalization for older adults and is associated with important consequences including increased morbidity and mortality, increased use of health care resources, and increased caregiver burden. The potential role that family caregivers could play in delirium prevention and how nurses could facilitate family participation has been largely unexplored. The Calgary Family Intervention Model (CFIM), operating on the assumptions of a family-centered care philosophy, provided a framework for understanding the feasibility of family participation in delirium prevention efforts.

METHODS: A descriptive exploratory design using a convenience sample of 15 family caregivers of older hospitalized adults at a large teaching hospital was used to address the research questions. For the Family Participation Delirium Prevention Program (FPDPP),
family caregivers implemented five intervention protocols targeted toward four baseline risk factors for delirium and self-tracked daily intervention completion. Feasibility was based on rates of intervention completion, and consideration of the barriers and facilitators for participation based on older adults’ and family caregivers’ responses on discharge questionnaires and staff nurses’ responses on a questionnaire.

RESULTS: Intervention completion was highest for the orientation protocol (83.5%), followed by the vision protocol (81.5%), therapeutic activities protocol (76.9%), hearing protocol (73.6%), and early mobilization protocol (55.3%). Three themes emerged on the barriers and facilitators for family participation: therapeutic relationships, partnership, and environment. The barriers and facilitators were generally consistent with the concept of family-centered care as described in the CFIM.

CONCLUSION: Based on the rates of intervention completion, it appears that the FPDPP is feasible for implementation in clinical practice. A remarkable level of agreement was found on the concept of the feasibility of family participation among older adult patients, family caregivers, and staff nurses with the common themes that emerged. Key to its successful implementation will be recognition and attention to the barriers and facilitators for participation. In addition, operating from a framework of family-centered care, nurses can advocate for environments that support family caregivers’ participation in a delirium prevention program.
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CHAPTER 1
INTRODUCTION

Background and Significance

Delirium is a major burden to healthcare systems and has been largely ignored by health services planners and practitioners (Inouye, Schlesinger, & Lydon, 1999). In addition, healthcare systems often unintentionally stimulate or aggravate the development of delirium in older adults (McCusker et al., 2001). This might be understandable if delirium was unavoidable, but the existing evidence base for delirium is sufficiently strong for prevention of the condition to be a realistic proposition. There is a pressing need to conduct research in this area because the outcomes for patients who develop delirium are poor. Delirium contributes to substantial morbidity and mortality, causes considerable distress to patients and families, and is expensive to treat (Inouye, 2006; Young & Inouye, 2007).

Delirium is the leading complication of hospitalization for older adults (Inouye, 2006; Inouye & Charpentier, 1996; Inouye et al. 1999; Milisen et al., 2001; O’Keeffe & Lavan, 1997; Young & Inouye, 2007). A systematic review that identified 42 studies on delirium in medical inpatients found that the occurrence of delirium varied between 11% and 42% (Siddiqi, Horne, House, & Holmes, 2006). The development of delirium is associated with important negative consequences such as increased mortality, increased morbidity as a result of greater functional loss, higher incidence of pressure ulcers, and incontinence, protracted hospital stay, increased use of health care resources and, greater burden for caregivers (Cole, 2004; Inouye, Rushing, Foreman, Palmeiri, & Pompei, 1998; McCusker, Cole, Dendukuri, & Belzile, 2003; O’Keeffe & Lavan, 1997). Evidence also
suggests that symptoms persist in about a third of patients (Siddiqi et al., 2006), and that these patients have a poor prognosis (McAvay et al., 2006).

Substantial additional costs accrue after hospital discharge because of the need for institutionalization, rehabilitation services, formal home health care, and informal caregiving for patients who continue to be delirious (Inouye, 2006). Total cost estimates attributable to delirium range from $16,303 to $64,421 per patient resulting in a financial burden of $38 billion to $152 billion each year (Leslie, Marcantonio, Zhang, Leo-Summers & Inouye, 2008). After spending an estimated additional $2,500 per patient, with a $6.9 billion annual expenditure in 2004 (U. S. Department of Health and Human Services, 2004), Medicare could save 1-2 billion dollars annually if hospital stays for each patient with delirium could be reduced by just one day (Demeure & Fain, 2006).

Older adults with chronic conditions, physiological impairments, decreased reserve, and numerous medications represent a group especially vulnerable to the adverse effects of hospitalization, including delirium. Because hospitalization of older adults accounts for greater than 49% of all days of hospital care, the potential for the occurrence of delirium is high (The Administration on Aging, 2004). Primary prevention of this complication is therefore of paramount importance to patients, families, and health care institutions because of the physical, emotional, and financial burdens of caring for the older adult who is suffering from delirium.

A number of studies have examined the efficacy of multicomponent interventions for delirium prevention, all implemented by interdisciplinary care providers. The potential role that family caregivers could play in delirium prevention in the older adult population and how nurses could facilitate this process has been unexplored. More
research needs to be completed in order to devise a program that includes family
caregivers in these important efforts. Family caregivers are an untapped resource who
can collaborate with nurses to deliver multicomponent interventions to decrease the
incidence of delirium in the older hospitalized adult. Including family caregivers in the
patient’s plan of care has been suggested as integral to increasing the quality of care for
older adults and improving patient outcomes (Haesler, Bauer, & Nay, 2007). Therefore,
the results of this study have significant implications for clinical practice and for
organizational approaches that seek to improve patient safety, and other quality outcomes
for the vulnerable older adult population.

This investigation examined the feasibility of an established, targeted,
multicomponent intervention strategy, while contributing new information about the role
of family caregiver participation and the role of nurse support, as an additional dimension
to efforts aimed at decreasing the incidence of delirium in the older hospitalized adult.
The Calgary Family Intervention Model (CFIM) provided the conceptual framework
upon which this study was based. A descriptive exploratory design was used to address
the research questions. The Family Participation Delirium Prevention Program was
implemented on an inpatient general medicine unit at a large academic medical center.

**Purpose/Specific Aims**

Consistent with the main objective of the AHRQ’s patient safety mission of
improving the quality and safety of health care for all Americans, the primary aim of this
study was to examine the feasibility of a nurse-supported, multicomponent family
intervention program for delirium prevention in the older hospitalized adult. The Family
Participation Delirium Prevention Program (FPDPP) was implemented by family
caregivers with intermittent support from the nursing staff whose primary role was as a resource to family caregivers on protocol implementation. The FPDPP, which is described in detail in the Methods chapter, consists of five standardized intervention protocols (orientation protocol, therapeutic activities protocol, early mobilization protocol, vision protocol, hearing protocol), targeted toward four major delirium risk factors (cognitive impairment, activities of daily living (ADL) impairment, vision impairment, hearing impairment). A multicomponent intervention program that partners the nurse and the family caregiver may ultimately provide the most realistic approach to preventing the devastating consequence of delirium in the older hospitalized adult. The specific aims of this study were to track which of the assigned intervention protocols family caregivers completed, to identify barriers and facilitators to family participation, and to examine how nurses facilitate family participation.

**Research Questions**

The research questions that were addressed in this study include the following:

1. Which intervention protocols of the Family Participation Delirium Prevention Program (FPDPP) do family caregivers complete?
2. How often do family caregivers complete each of the assigned intervention protocols?
3. What are the facilitators of family participation in the FPDPP?
4. What are the barriers to family participation in the FPDPP?
5. How do nurses facilitate family participation in the FPDPP?
Preliminary Studies

Pilot Study

During the Fall of 2007, Ms. Rosenbloom-Brunton obtained Partners Human Subjects Committee and UMASS Institutional Review Board approval to conduct a pilot study to gather preliminary findings for the anticipated doctoral dissertation study. The focus of the pilot study was on the procedures for family caregiver training and implementation of the FPDPP. Data collection occurred during January of 2008, with enrollment of ten eligible older adult/family caregiver dyads from two study units at a large teaching hospital in Boston, MA over the course of one month.

The age range of enrolled older adults was 66 to 86 years. Family caregivers ranged in age from 29 to 82 years of age. There were five male and five female older adult patients who participated. Five of the family caregivers were spouses of an older adult patient, four were adult children of an older adult patient, and one was the sister of a patient. Four whites, two Hispanics, two Asians, and two Black older adult patients were enrolled. Family caregivers were of the same race and ethnicity as their older adult family member.

Intervention completion was highest for the orientation protocol (96%), followed by the vision (83%), hearing (82%) and therapeutic activities (72%) protocols. Lowest completion was for the early mobilization protocol (39%). Content analysis of responses to open-ended questions on the Family Caregiver Questionnaire resulted in five themes – three identified barriers to participation and two identified facilitators. Themes addressing barriers included:
1. *The rapid pace of the acute care environment.* Caregivers noted frequent interruptions, noise, and lack of privacy as major barriers to intervention completion.

2. *The older adult’s acutely ill state.* Pain, shortness of breath, fatigue, and nausea were identified as factors interfering with the older adult’s participation.

3. *Fear.* Caregivers expressed feeling ill-prepared to engage in activities with their acutely ill family member, especially early mobilization interventions.

Two additional themes identified facilitators of family participation. Nurses caring for the older adults acted to support the family caregivers’ participation in the FPDPP. The degree of support varied among the nurses. Nurse support activities were subsumed under two themes:

1. *Activities aimed at encouraging.* Family caregivers derived emotional support from validation by the nurses of their competence in successful intervention completion.

2. *Activities aimed at promoting an uninterrupted environment.* Family caregivers identified physical support for the environment through provision of uninterrupted time for intervention completion as important for successful completion of interventions.

Based on the preliminary findings of the pilot study for intervention completion rates, modifications to the early mobilization protocol to simplify the interventions and to the hearing protocol to support speech understanding of the older adult were made. It was hoped that this would support the main study’s outcomes of family caregiver participation and maintenance of cognitive status for the older adult. In addition for the
main study, support for the feasibility of the FPDPP was enhanced by the provision of a feedback questionnaire that could be completed by the staff nurse. This instrument was anonymous and voluntary, and would be made available daily for 14 days midway through data collection and again for 14 days after subject enrollment was closed. These sources of data would provide additional information to that derived from the family caregiver questionnaires on the barriers and facilitators for family participation in the FPDPP, including the role of nurse support from the family caregiver’s perspective.
CHAPTER 2
LITERATURE REVIEW

Delirium or acute confusional state is characterized by an acute disruption of cognition and attention (American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders (4th ed.), text revision, 2000*). Delirium is the leading complication of hospitalization for older adults with prevalence rates ranging from 11% to 42% (Siddiqi, Horne, House, & Holmes, 2006). The marked variability in the epidemiology of delirium results from the differences in study populations, diagnostic criteria, and research techniques. Nonetheless delirium is associated with important negative consequences such as increased morbidity and mortality; protracted hospital stay; increased use of health care resources both during inpatient stay and following discharge; and, greater burden for caregivers (Cole, 2004; Inouye, Rushing, Foreman, Palmeiri, & Pompei, 1998; O’Keeffe & Lavan, 1997).

**Risk Factors for Delirium**

A multifactorial etiology of delirium is the most common model used. For most older adults, several precipitants may exist. The complex interrelationship between a vulnerable patient with predisposing factors or underlying risk factors present before admission (Inouye et al., 1993), and exposure to precipitating factors or noxious insults during hospitalization contributes to its frequent occurrence in the older hospitalized adult (Inouye & Charpentier, 1996). The precipitants alone do not cause delirium, but interact with the underlying risk factors. A major insult, such as serious infection, may trigger delirium in a previously healthy person. However, even minor stressors, such as a
change in medication, can result in delirium in a person with many risk factors. Older adults with multiple chronic diseases are therefore especially prone to delirium.

Systematic reviews have assessed studies investigating independent risk factors for delirium in hospitalized patients (Inouye, 1999; Kirshner, 2007; Young & Inouye, 2007). Commonly encountered predisposing risk factors and precipitants for delirium are listed in Table 1. The most common risk factor identified across studies was cognitive impairment. Environmental risk factors for delirium include moves within the hospital, absence of a clock or watch, absence of reading glasses or hearing aids, no presence of family member, and use of restraints (physical or chemical) (McCusker et al., 2001).

### Table 1: Common Risk Factors for Delirium

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<td>Physical frailty</td>
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<tr>
<td>Severe illness</td>
<td>Multiple diseases</td>
</tr>
<tr>
<td>Polypharmacy</td>
<td>Alcohol excess</td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td>Visual impairment</td>
</tr>
<tr>
<td>Hearing impairment</td>
<td>Renal impairment</td>
</tr>
<tr>
<td>Admission to the hospital with infection or dehydration</td>
<td>Malnutrition</td>
</tr>
<tr>
<td>Lower respiratory tract infection</td>
<td>Immobility</td>
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<tr>
<td>Urinary infection or urinary catheters</td>
<td>Surgery</td>
</tr>
<tr>
<td>Constipation</td>
<td>Electrolyte disturbances</td>
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<tr>
<td>Pain</td>
<td>Sleep deprivation</td>
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<td>Environmental (see text)</td>
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</table>

Four major risk factors for delirium (cognitive impairment, ADL impairment, vision impairment, hearing impairment) have been previously identified as having predictive significance for the occurrence of delirium. (Inouye et al., 1993; Korevaar, van Munster, & deRooij, 2005). In both studies, univariate logistic regression analysis was used to identify risk factors for delirium. Multivariate logistic regression was then used to
identify the independent contributions of the identified risk factors to the outcome of delirium. Adjusted odds ratios and 95% confidence intervals for the significant risk factors included: vision (3.51, 1.15-10.71, p< 0.05), hearing (2.0, 0.9-4.6, p<0.05), and cognitive impairment (2.82, 1.19-6.65, p< 0.05) (Inouye et al., 1993); and cognitive impairment (9.48, 2.27-39.54, p< 0.01) and functional impairment (14.13, 2.26-88.24, p< 0.01) (Korevaar et al., 2005). The intervention protocols for these risk factors all involve activities that family caregivers typically perform in daily care activities. Understanding the risk factors for delirium provides an important opportunity to identify patients at high risk of developing the condition and target these patients with preventive interventions.

**Multicomponent Interventions for Delirium**

The etiology of delirium is believed to be intrinsically multifactorial with a number of factors contributing to increased risk. Therefore, for an intervention strategy to be effective, it should target the multifactorial origins of delirium with multicomponent interventions that include more than one activity (Inouye et al., 1999; Inouye, 2006). Multicomponent interventions when implemented by an interdisciplinary team of health care providers have previously been demonstrated to be the most effective strategy for delirium prevention because they recognize the multifactorial etiology of delirium (Inouye, 2006; Naughton et al., 2005). However, there are limitations to the implementation of multicomponent interventions including the availability of resources and the coordination of implementation. The most successful preventive intervention programs also include assessment and treatment of risk factors to minimize risk (Cole et al., 2002; Flaherty, Raghavan, Bakshi, Moinuddin, & Morley, 2003; Inouye et al., 1999; Lundstrom, Edlund, Lundstrom, & Gustafson, 1999; Milisen et al., 2001; Rapp, 2001).
Multicomponent models of care that effectively prevent incident delirium for medical patients in the hospital setting have been developed and tested (Cole et al., 2002; Flaherty et al., 2003; Inouye et al., 1999; Lundstrom et al., 1999; Rapp, 2001), most notably the Hospital Elder Life Program (Inouye, Bogardus, Baker, Leo-Summers, & Cooney, 2000). In the Delirium Prevention Trial, Inouye et al. (1999) were the first to use a standardized multicomponent intervention strategy; 852 patients of at least 70 years of age were randomized to an intervention or usual care group. The intervention consisted of eight standardized protocols for the management of six major risk factors for delirium (cognitive impairment, sleep deprivation, immobility, visual impairment, hearing impairment, and dehydration) which had been identified in previous research (Inouye et al., 1993; 1996). Table 2 describes the risk group that received each intervention, and the standardized intervention protocols for each risk factor. The standardized intervention protocols were developed from the findings of a systematic review of effective interventions for delirium prevention (Cole, 1999). In the Delirium Prevention Trial, the risk of developing delirium during hospitalization of the experimental group who received the multicomponent intervention decreased by 40%, compared to no change in the control group.
<table>
<thead>
<tr>
<th>Targeted Risk Factor and Eligible Patients</th>
<th>Standardized Intervention Protocols</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive impairment</strong></td>
<td>Orientation protocol: Board with names of care team members and day’s schedule; communication to reorient to surroundings</td>
</tr>
<tr>
<td>All patients, protocol once daily; patients with baseline Mini Mental State Examination score (MMSE) &lt; 20, protocol three times daily</td>
<td><strong>Therapeutic-activities protocol:</strong> Cognitively stimulating activities three times daily (e.g. discussion of current events; structured reminiscence, word games)</td>
</tr>
<tr>
<td><strong>Sleep deprivation</strong></td>
<td>Nonpharmacologic sleep protocol: At bedtime, warm drink (milk or herbal tea), relaxation tapes or music, and back massage</td>
</tr>
<tr>
<td>All patients; need for protocol assessed once daily</td>
<td><strong>Sleep-enhancement protocol:</strong> Unit-wide noise reduction strategies (silent pill crushers, vibrating beepers, quiet hallways) and rescheduling of medications/procedures to allow sleep</td>
</tr>
<tr>
<td><strong>Immobility</strong></td>
<td>Early mobilization protocol: Ambulation or active range-of-motion exercises three times daily; minimize use of immobilizing equipment (restraints, catheters)</td>
</tr>
<tr>
<td>All patients; ambulation whenever possible and range-of-motion exercises when non-ambulatory, bed or wheelchair bound, immobilized (e.g. extremity fracture or deep vein thrombosis)</td>
<td><strong>Vision protocol:</strong> Visual aids (e.g. glasses or magnifying lenses) and adaptive equipment (e.g. large illuminated telephone keypads, large-print books, and fluorescent tape on call bell) with daily reinforcement of their use</td>
</tr>
<tr>
<td><strong>Visual impairment</strong></td>
<td><strong>Hearing protocol:</strong> Portable amplifying devices, earwax disimpaction and special communication techniques, with daily reinforcement of their use</td>
</tr>
<tr>
<td>Patients with visual acuity worse than 20/70 on binocular near vision testing</td>
<td><strong>Dehydration protocol:</strong> Early recognition of dehydration and volume repletion (e.g. encouragement of oral intake of fluids)</td>
</tr>
<tr>
<td><strong>Hearing impairment</strong></td>
<td><strong>Dehydration protocol:</strong> Early recognition of dehydration and volume repletion (e.g. encouragement of oral intake of fluids)</td>
</tr>
<tr>
<td>Patients hearing &lt;=6/12 whispers on Whisper Test</td>
<td><strong>Dehydration protocol:</strong> Early recognition of dehydration and volume repletion (e.g. encouragement of oral intake of fluids)</td>
</tr>
<tr>
<td><strong>Dehydration</strong></td>
<td><strong>Dehydration protocol:</strong> Early recognition of dehydration and volume repletion (e.g. encouragement of oral intake of fluids)</td>
</tr>
<tr>
<td>Patients with ratio of blood urea nitrogen to creatinine&gt;=18</td>
<td><strong>Dehydration protocol:</strong> Early recognition of dehydration and volume repletion (e.g. encouragement of oral intake of fluids)</td>
</tr>
</tbody>
</table>

From the findings of the Delirium Prevention Trial, The Hospital Elder Life Program (HELP) was developed as an innovative model of care designed to prevent delirium and functional decline in hospitalized older adults (Inouye et al., 2000). The HELP program consists of an interdisciplinary staff (geriatric nurse specialist, a physical therapy consultant, a geriatrician, and trained volunteers) who implement the above eight intervention protocols targeted toward the six major delirium risk factors (see Table 2). The unique strengths of the HELP model include: the targeted nature of the interventions, early intervention focusing on prevention, well-trained interdisciplinary staff dedicated to the program, standardized intervention protocols, tracking of adherence to all protocols, and built-in quality assurance procedures (Inouye et al., 2000). A cross sectional questionnaire of thirteen sites across the country which have enrolled a total of 11,344 patients showed patient and family satisfaction rates at 92.3% and improvement in quality of care at 84.6% (Inouye, Baker, Fugal, & Bradley, 2006), versus the standard rates of 82% and 61.5% respectively found in the National Hospital Discharge Survey 2005 (DeFrances, Hall, & Podgornik, 2006).

A study by Marcantonio, Flacker, Wright, & Resnick (2001) reported a reduction in the incidence of delirium in 126 elderly hip fracture patients using a proactive geriatrics consultation and multicomponent approach. Lundstrom et al. (1999) found that reorganization of nursing and medical care on an orthogeriatric rehabilitation unit, which involved staff education, active nutrition, improvement of the unit environment, continuity of care, and planning of rehabilitation, greatly reduced the incidence of delirium in elderly patients with femoral neck fractures. However, in a randomized study of 120 elderly hip fracture patients, a standardized intervention consisting of education of
nursing staff, systematic cognitive screening, specialized consultation, and a scheduled
pain protocol was not statistically significant with respect to decreasing the incidence of
delirium, although severity and duration of delirium were reduced (Milisen et al., 2001).

The Calgary Family Intervention Model (CFIM) (Wright & Leahey, 1984, 2000)
which has been used to test interventions that involve the patient and family to improve
outcomes of care supports a multicomponent approach to delirium prevention.

According to the model, it is not one, but several factors that enhance the likelihood that
interventions will be more effective and useful to patients and families. The assumption
of the CFIM is that the nurse and the family, in interaction, can affect the patient’s health.

The CFIM guides intervention implementation by suggesting that family interventions
should be related to the problems that the nurse, patient, and family have collaborated on.

The CFIM provides the theoretical basis for a collaborative effort between the nurse and
the family in a multicomponent intervention program to prevent delirium in the older
hospitalized adult.

**Family Caregiver Interventions**

Family caregiver interventions for delirium have had limited study. Chatham
(1978) undertook an early study to determine if the quality of patient-family interactions
in an intensive care unit (ICU) during the first four days after open-heart surgery would
influence the patient’s postoperative behavior. Preoperatively, family caregivers received
systematic instruction that included information on the functions of the ICU equipment,
postoperative care routine, and the patient’s need for eye contact, frequent touch, and
verbal orientation to time, place, and person. Postcardiotomy behaviors were assessed
using an eleven-item behavioral checklist (Quinlin, Kimball, & Osbourne, 1974). Trained
involvement of significant family members was found to favorably affect five behaviors of subjects in the experimental group which included orientation, appropriateness, confusion, delusion, and sleep. The authors concluded that further study of trained involvement of family members in the care of critically ill patients and additional ways of involving family members should be investigated.

In the only other published study on family caregiver interventions for delirium, a psychoeducational intervention was implemented in a palliative care hospice to help family caregivers cope with delirium in a family member with a terminal diagnosis (Gagnon et al., 2002). Using the perspectives of family caregivers elicited from focus groups, the goal of the study was to develop and test an intervention to educate caregivers about delirium and to teach skills for managing the symptoms. The effect of the psychoeducational intervention on prevention of delirium was not considered. The psychoeducational intervention, which consisted of a brochure on delirium symptoms, causes, and treatment strategies for family caregivers, was verbally given by the bedside nurse who adjusted the content and extent of the information to the needs of family caregivers. Knowledge of delirium and perceived competence in decision-making ability for family caregivers were significantly improved in the intervention group (p<0.006). Outcomes for patients whose caregivers received the psychoeducational intervention were not studied.

**Summary**

The primary aim of this study was to examine the feasibility of a nurse-supported, multicomponent family intervention program for delirium prevention in the older hospitalized adult. It has been demonstrated that there is a need for further development
of knowledge in the area of delirium prevention interventions. Previous multicomponent intervention studies have been limited to interdisciplinary care providers implementing the intervention programs, and more information needs to be collected on the desire of family caregivers to assume an active role.

Even though the preceding results are encouraging in terms of the potential efficacy of both multicomponent and family caregiver interventions for delirium, the extent of the research is limited. In addition, the two published family caregiver intervention studies both examined the effect of family interventions on the family caregiver, yet did not examine the impact on the incidence of delirium in the older hospitalized adult. The study reported here adds to the body of knowledge around delirium prevention. Its strength lies in the use of a multicomponent targeted intervention strategy that has been proved effective for decreasing the incidence of delirium in the older hospitalized adult during the previously completed Delirium Prevention Trial. Its innovation lies in the modification of the intervention program for family implementation including an evaluation of the family’s perception of the role of nurse support, while giving consideration to the unique needs of family caregivers and older adult patients.
CHAPTER 3

FRAMEWORK

Calgary Family Intervention Model

The Calgary Family Intervention Model (CFIM) (Wright & Leahey, 1984, 2000) is the only family intervention model to have emerged within the discipline of nursing. The importance and effectiveness of family interventions in the treatment of physical illness has received recognition, specifically to help families use the strengths of individual family members and of the family as a unit to improve health (Campbell & Patterson, 1995; Feeley & Gottleib, 2000). The CFIM has been used extensively as the conceptual framework for studies operating on the assumptions of a family-centered care philosophy and to test interventions that involve the patient and family to improve outcomes of care (Addington, Collins, McCleery, & Addington, 2005; Martin-Arafah, Watson, & Baird, 1999; Riley-Doucet, 2005; Simpson, Yeung, Kwan, Wah, 2006).

The CFIM integrates nursing and family therapy concepts grounded in systems theory, change theory, second order cybernetics, and the biology of cognition. The assumptions from general systems theory and family systems theory help change the focus of one’s conceptual lens from parts to wholes and include: (1) a family system is part of a larger suprasystem; (2) the family as a whole is greater than the sum of its parts; (3) a change in one family member affects all family members; (4) the family is able to create a balance between change and stability; and, (5) family members’ behaviors are best understood from a perspective of circular rather than linear causality (Wright & Leahey, 2000, pp. 38-44). Therefore, it is important for nurses to appreciate the family as
the context for the individual, influencing the individual’s development across the lifespan and adaptation in times of change.

The core of nursing interventions is helping families to change. Families need a balance between change and stability to maintain equilibrium. Concepts from change theory underpinning the CFIM include that change is dependent on perception of the problem, the context, and coevolving goals for treatment. Wright and Leahey (2000, pp. 46-49) suggest that the nurse facilitates change by means of a “fit” between the interventions offered and the biopsychosocial-spiritual structures of family members. The assumption of second order cybernetics that informs the CFIM is that individuals draw forth reality – they do not construct it (Maturana & Varela, 1992). This has important implications for nurses working with patients and families. Nurses join patients and families in a social construction of a therapeutic reality.

The CFIM is the first and still only family nursing intervention model. The CFIM is an organizing framework conceptualizing the intersect between a particular domain of family functioning (e.g. cognitive, affective, behavioral), and a specific intervention offered by a nurse. It is based on the assumption that evaluation of the family reveals what impact the illness has had on the family and how the family can affect the patient's health outcomes. In addition, the CFIM appreciates that openness to certain interventions is profoundly influenced by the relationship between the patient, nurse, and family (Bohn, Wright, & Moules, 2003; Duhamel & Talbot, 2004; Leahey & Harper-Jacques, 1996). The CFIM guides intervention implementation by suggesting that interventions should be related to the problems that the nurse, patient, and family have collaborated on.
Family Nursing Interventions

The CFIM is based on an appreciation that the most rewarding aspect of the nursing of families is to observe families healing from emotional and/or physical suffering. This healing can occur through families' own efforts or in collaboration with nurses. When healing occurs in collaboration with nurses, it is because families and nurses coevolve useful solutions to particular health problems. Nursing's contribution to this collaborative process is knowledgeable and competent nursing practice with families. This is accomplished through the therapeutic offering of effective and useful interventions.

Only recently have nurses begun to engage in critical dialogue about nursing interventions in general. The identification of family nursing interventions is even more rare. As a family nursing intervention model, the CFIM suggests that if we are to improve our therapeutic practice by including families, it is essential that we become more knowledgeable about what interventions families find most useful and that we address the question of how nurses become competent in the offering of those interventions (Robinson, Wright, & Watson, 1994).

Wright and Bell (1990) propose the following definition of a nursing intervention: any action or response of the nurse, which includes the nurse's overt therapeutic actions, that occur in the context of a nurse-patient relationship to affect individual, family, or community functioning for which nurses are accountable (p. 3). An important aspect of this definition is the recognition of the interactional or relational aspect of interventions, that is, interventions are only actualized in a relationship (Wright & Leahey, 1994).
Interventions are the responses of the nurse that are invited by the responses of the family that in turn are invited by the responses of the nurse.

**Relevance for the FPDPP**

The CFIM, which is a family nursing intervention model, is one way that health care professionals can conceptualize family support and provides a framework for understanding how nurses can support family caregivers’ participation in a multicomponent intervention program for delirium prevention in the older hospitalized adult. According to the model, several factors enhance the likelihood that family nursing interventions will be more effective and useful to patients and families. This study was based on the assumption that family participation may be profoundly influenced by the relationship between the nurse and the family.

The theoretical substruction of the research study is presented in Appendix A, with the components based on the CFIM in boldface. Patient outcomes of care, including adverse events such as delirium, may be affected not only by the care provided by the nurse and by the family, but also by the interactions between the family and the nurse. In the CFIM, the broad constructs include: (1) the nurse; (2) the family; (3) the patient; and (4) an interaction, which form the most abstract proposition (axiom) of the theoretical explanation. The axiom states that the nurse and the family, in interaction, can affect the patient’s health. These constructs provide the theoretical basis for a collaborative effort between the nurse and the family in a multicomponent intervention program to prevent delirium in the older hospitalized adult.

The CFIM consists of three major concepts: (1) interventions (by the nurse); (2) needs of family caregivers; and, (3) the “fit” between them. The proposition that links
the concepts states that interventions should be fit to the needs of the family. For this study, nursing interventions are conceptualized as supportive nursing behaviors (as identified by family caregivers in questionnaire responses). These components intersect to impact the outcomes, which include the participation in the intervention program by the family caregiver and the maintenance of cognitive status for the older hospitalized adult.

Interventions are conceptualized as the core of clinical practice and can be targeted to promote, improve, or sustain health. The family nursing intervention process provides an opportunity where the family can have identified needs, within the context of care of the older hospitalized adult, met. The CFIM provides the framework for understanding that nursing interventions, which are conceptualized as supportive nursing behaviors identified by the family caregiver, promote family participation in the FPDPP. In this study, barriers and facilitators of family participation in delirium prevention efforts, including nursing supportive behaviors, are described as part of the development and future testing of a family-implemented delirium prevention program that is feasible for family participation.
CHAPTER 4

METHODS AND PROCEDURES

Research Design

A descriptive exploratory design was used to address the research questions of this study. The use of a descriptive exploratory design was selected to gain information about family participation in a multicomponent intervention for delirium prevention. Before the effect of a family implemented multicomponent intervention program on the incidence of delirium can be examined, there is a need for clearer delineation of family caregivers’ desired role and the potential impact of nurse support.

Population and Sample

The population of interest in this study included family caregivers, defined as a spouse, blood relative or significant other, of hospitalized adults, age 65 or older. This broad definition of family caregivers has consistently been used in family intervention research and reflects the variety of relationships that individuals include in defining family structure (Acton & Kang, 2001). An older adult inpatient medical population was selected because the protocols of the FPDPP were modified from those of the HELP program, which was originally tested in a medical population and found to decrease the incidence of delirium by 40%.

A nonprobability sampling strategy was employed to obtain a convenience sample of family caregivers of hospitalized patients, age 65 or greater, based on the daily census of newly admitted patients. The intent was to have at least ten family caregivers participate in the FPDPP, track completion of assigned interventions, and complete a questionnaire upon discharge of the older adult. Because the purpose of this study was to
examine feasibility, sample size estimates were not computed and, instead, the number of caregivers enrolled was based on previous research. In the one published study to date examining the feasibility of a family intervention, Svavarsdottir and Sigurdardottir (2006) examined the feasibility of a family level intervention for parents of children newly diagnosed with cancer. The authors asked ten family caregivers of children newly diagnosed with cancer to complete questionnaires at baseline and then twice after the intervention, at six and twelve months. The questionnaires were designed to elicit information on the likelihood of parents’ participation in a similar family intervention. From this sample of ten family caregivers, all indicated that they would plan to participate and that the program was feasible for implementation, therefore it was determined that offering a family level intervention was feasible. These results suggest that ten family caregivers would provide adequate data to assess feasibility of the FPDPP.

Inclusion criteria for the accessible population are summarized in Table 3. The selection criteria for this study were not based on gender, race, or ethnicity. There were no scientific reasons to anticipate differences between gender, racial, and ethnic groups with regard to the research questions under examination. The inclusion criteria were designed to be as inclusive as possible and to assure that family caregivers and patients, by having at least one targeted risk factor for delirium, would benefit from the program.
Table 3: Inclusion Criteria for Subjects

<table>
<thead>
<tr>
<th>Older Adult</th>
<th>Family Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 65 or older</td>
<td>Spouse, blood relative, or significant other of eligible older adults</td>
</tr>
<tr>
<td>Inpatient admission to the designated study unit</td>
<td>Able to read, write, and communicate in English</td>
</tr>
<tr>
<td>At least one of the four targeted risk factors for delirium at baseline screening (cognitive impairment, ADL impairment, vision impairment, hearing impairment)</td>
<td>Able to visit daily for intervention protocol completion</td>
</tr>
<tr>
<td>Able to read, write, and communicate in English</td>
<td></td>
</tr>
</tbody>
</table>

Exclusion criteria are summarized in Table 4. Exclusion was minimized by confirmation with the dissertation advisor, a patient safety, acute care nursing expert.

Table 4: Exclusion Criteria for Subjects

<table>
<thead>
<tr>
<th>Older Adult</th>
<th>Family Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Presence of delirium at baseline</td>
<td>Refusal by the family caregiver</td>
</tr>
<tr>
<td>Patient factors that preclude verbal communication (coma, mechanical ventilation, severe aphasia, profound dementia; severe/profound hearing loss (≤ 2/12 score on Whisper test in corrected state)</td>
<td></td>
</tr>
<tr>
<td>Combative behavior, severe psychotic disorder</td>
<td></td>
</tr>
<tr>
<td>Airborne precautions (TB, measles)</td>
<td></td>
</tr>
<tr>
<td>Anticipated discharge within 48 hours</td>
<td></td>
</tr>
<tr>
<td>Refusal by the patient, family caregiver, or physician</td>
<td></td>
</tr>
</tbody>
</table>

Setting

The setting was an inpatient acute medical unit at a 900-bed academic medical center which is largest hospital in New England and conducts the largest hospital-based research program in the United States. The facility has 312 designated non-intensive care general medical beds (44% of total beds), with 50% of patients being age 65 or older. During 2008, medical beds were filled at 100% occupancy. Admitting diagnoses for
medical units represent a diverse adult population with a wide range of complex medical
problems. Since adults age 65 or older, who are a population at increased risk for
delirium, account for greater than 49% of all days of hospital care in the United States,
and admitting statistics at the study hospital reflect this trend, the availability of eligible
subjects on medical units in the study setting was determined to be feasible. Table 5 lists
census statistics for the study unit.

Table 5: Census Statistics, Study Unit, 2007-2008

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of beds</th>
<th>Admissions per year</th>
<th>Average LOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>25</td>
<td>1,620</td>
<td>5.4 days</td>
</tr>
<tr>
<td>2008</td>
<td>25</td>
<td>1,799</td>
<td>5.2 days</td>
</tr>
</tbody>
</table>

The study unit had access to a family lounge with a relaxed environment where
family caregivers could review intervention protocols, complete tracking sheets, and
complete the family caregiver questionnaire.

**Consortium/Contractual Arrangements**

**Resources/Facilities**

Resources and facilities to support the proposed study included academic and
research support services available at the University of Massachusetts Amherst, the
academic partner in this proposal, and those at Massachusetts General Hospital, the
practice partner in this proposal. Appendix B summarizes resources and facilities.

**Collaborative Arrangements**

Support for access to the acute medical unit at the study hospital was confirmed
with the leadership team for the unit. Study protocol direct care requirements were
completed by the principal investigator and research assistants. Before data collection
began, a staff meeting with the Practice Committee on the study unit was held where the study was presented and questions and concerns were addressed.

**Consultative Support**

The research team was uniquely qualified to address the feasibility of a family protocol for delirium prevention in the older hospitalized adult. The team included nurses, physicians, scientists, and experts in communication and biostatistics who had specific experience and expertise to contribute to the study. Appendix C lists members of the support team.

**Ethical Considerations/Human Subjects**

**Protection of Human Subjects**

The major risk in a study with family caregivers delivering an intervention to an older adult is burden to the older adult for reasons related to admitting diagnosis and co-morbidities. To address this, all of the intervention protocols included activities that are commonly used by family caregivers in their daily interactions and caregiving activities with older adults. There is also a risk for the family caregiver that the requirement for daily visits causes disruptions in the caregivers life that would not otherwise occur. During the informed consent process and during intervention training, the family caregiver received honest and realistic information about the potential time that a visit may require (1/2-2 hours) so that they could make an informed decision. The family caregiver training session was limited to a one hour session with the principal investigator or a research assistant, arranged at a convenient time for the family caregiver.
The proposal was approved by both the Partners Health Care Systems Human Subjects Committee via expedited review and the University of Massachusetts (UMASS) Amherst Institutional Review Board. The principal investigator and research assistants completed the Collaborative IRB Training Initiative (CITI) course in *The Protection of Human Research Subjects* directed by the University of Miami and the Fred Hutchinson Cancer Research Center.

To ensure confidentiality, study data and patient identification information were maintained in separate files which were stored in separate locations. Each older adult and family caregiver subject was assigned a unique study identification number (study ID) and their link to individual identification maintained in a “master list”. The “master list” was stored in a locked file cabinet in the principal investigator’s secure office at the MGH Institute of Health Professions. Separately, in the study file, older adult subjects and their caregivers were identified by their study ID only. All data was entered into a password-safe computerized system. All of the members of the research team completed the Health Insurance Portability and Accountability Act (HIPAA) training. The medical record and data collection tools were considered data sources in the study and were handled by only the principal investigator and research assistants.

Informed consent was obtained from the older adult and the family caregiver, both verbally and in writing, by the principal investigator. This occurred after discussion of study procedures, risks, benefits, and alternatives. The original signed consent forms were retained in a locked file cabinet in the principal investigator’s office and copies were given to the subjects. The informed consent forms for older adult patients and family caregivers are included in Appendix D and Appendix E.
Data and Safety Monitoring Plan

The safety of the subjects in the study involved minimal risk because the intervention protocols involved activities that were consistent with the usual care delivered by family members. The major difference was the targeting of interventions toward risk factors and the standardization of the strategies used. To ensure that the rights and safety of subjects were maintained, the principal researcher reviewed the Family Caregiver Tracking Sheets daily for the occurrence of any adverse events, including the occurrence of delirium. If any serious adverse event occurred during the course of the study (of which there were none), the plan was to immediately communicate the occurrence to the medical/inpatient team managing the patient’s care. In addition, within 24 hours of the event, a verbal report would be given to the Partners Human Research Committee (PHRC), followed by a full written report within ten working days using the PHRC Adverse Event form. Mild or moderate adverse events (of which there were none) would have been summarized in a progress report at the continuing review. Any older adult, who developed delirium during data collection (of which there were none), as operationalized by the Confusion Assessment Method criteria (Inouye et al., 1990) or by diagnosis by the house physician, would have been removed from the study so that the medical team could focus on treating the cause and reversing the acute change in cognitive status.

Inclusion of Women and Minorities

It was estimated that the sample would consist of approximately equal numbers of male and female subjects based on statistics for admission by gender for the study setting. Approximately seventy-five percent of the sample was anticipated to be white, with
thirteen percent being Hispanic or Black. The remaining percentages of subjects for race/ethnicity were anticipated to be Asian or other. This would reflect a representative sample based on race/ethnicity statistics reported in the 2005 American Community Questionnaire (United States Census Bureau, 2005). Table 6 lists patient information by gender, race and ethnicity at the study hospital for 2007.

Table 6: Gender, Race and Ethnicity for Inpatient Population, 2007

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Females</th>
<th>Males</th>
<th>Total</th>
<th>% by race and ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totals</td>
<td>267,205</td>
<td>233,167</td>
<td>500,373</td>
<td></td>
</tr>
<tr>
<td>% by gender</td>
<td>53.4%</td>
<td>46.6%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>22,862</td>
<td>21,018</td>
<td>43,880</td>
<td>8.77%</td>
</tr>
<tr>
<td>Asian</td>
<td>9,908</td>
<td>7,346</td>
<td>17,254</td>
<td>3.45%</td>
</tr>
<tr>
<td>White</td>
<td>203,142</td>
<td>175,954</td>
<td>379,096</td>
<td>75.76%</td>
</tr>
<tr>
<td>Black or African American</td>
<td>12,915</td>
<td>11,427</td>
<td>24,342</td>
<td>4.87%</td>
</tr>
<tr>
<td>Other</td>
<td>29,948</td>
<td>28,302</td>
<td>58,250</td>
<td>11.64%</td>
</tr>
<tr>
<td>Total</td>
<td>267,206</td>
<td>233,167</td>
<td>500,373</td>
<td></td>
</tr>
</tbody>
</table>

Data Collection

Subject Enrollment

Based on the daily census for the study unit, all newly admitted patients received a recruitment letter on admission from the admitting nurse. The recruitment letter, which was signed by both the patient’s house physician and the principal investigator, explained the purpose of the study and the nature and extent of subject involvement (see Appendix F).

Within twenty-four hours of admission to the study unit, all patients age 65 or older were invited to participate in the study by the principal investigator. The consent process for newly admitted older adult inpatients included a verbal review by the
principal investigator of all elements of the IRB-approved written consent form. This form described the purpose of the research; study procedures; risks and discomforts, as well as potential benefits associated with participation; alternative therapies; and, maintenance of confidentiality of records. The ESC was then administered, with scoring completed at the bedside based on a predetermined list of acceptable responses according to the study protocol (see Appendix G). Evidence of the ability to sign consent was based on correct responses to all five items on the ESC.

If the patient consented to participate (see Appendix D), the subject was then screened for at least one of the targeted risk factors (cognitive impairment, ADL impairment, vision impairment, hearing impairment), and for the presence of delirium using standardized assessment tools for measurement. Demographic data was obtained from the Partners Health Care System computerized medical record. The patient was asked to identify the significant family caregiver with whom they have the closest relationship. Within forty-eight hours of the older adult’s admission, the identified family caregiver was contacted by the principal investigator to offer participation. Once informed consent was obtained by the principal investigator (see Appendix E), family caregivers completed a demographic questionnaire (Appendix H).

**Intervention Program**

The development of the Family Participation Delirium Prevention Program (FPDPP) was completed with consultation from Sharon Inouye, MD, PhD, Professor of Medicine, Harvard Medical School, and Director of the Aging Brain Center, Institute for Aging Research, Hebrew Senior Life. The original protocols of the Hospital Elder Life Program (HELP) were adapted with permission from the HELP program (HELP
copyright, 2000; see Appendix I), with revisions based on preliminary findings from the pilot study completed in January of 2008 by the principal investigator (see Introduction chapter). Following the pilot study, modification of the early mobilization protocols occurred based on the findings of lower completion rates (39%), which family caregivers attributed to the complexity of the interventions. In addition, based on expert consultation from Dr. Karen Helfer, Graduate Program Director, Department of Communication Disorders, UMASS Amherst, the hearing protocol was modified to include the elements of the Clear Speech method (Schum, 1997).

Clear speech is one of the most effective methods to improve speech reception by the hearing impaired listener and can result in immediate improvement in speech recognition. Clear speech involves the speaker attempting to express every word and sentence in a precise, accurate, and fully formed manner. It is naturally slower and louder with a full range of voice intonation (tone) and stress on key words. The family caregivers participating in the FPDPP were taught to communicate with the older adult using the clear speech method. The family caregivers learned to clearly enunciate and increase the spacing between words which decreases the rate of speech. The goal was to enhance the ability of older adults to perceive spoken information correctly in order to support orientation.

The intervention, called the Family Participation Delirium Prevention Program (FPDPP), was implemented by the family caregiver who was trained in the protocols by the principal investigator. The previously described four risk factors for delirium were targeted for intervention by the five protocols. The orientation and therapeutic activities protocols targeted cognitive impairment; early mobilization protocol targeted ADL
impairment; vision protocol targeted vision impairment; and hearing protocol targeted hearing impairment. Details of the intervention protocols are described in Appendix J. These interventions were selected for their appropriateness and safety for family implementation since the protocols involved activities commonly performed by caregivers for older adults at home.

The training for family caregivers included a one-hour session with a member of the research team reviewing a training manual detailing the FPDPP protocols (see Appendix J). Family caregivers were allowed to keep the manual for reference. The family caregiver training procedure was based on the standardized training manual used to train volunteers to deliver the intervention protocols in the Delirium Prevention Trial, but was developed specifically for family caregivers. Family caregivers were instructed in charting procedures for documenting intervention completion on the Family Caregiver Tracking Form (see Appendix K). The value of recording both the completion of the intervention, its non-completion, plus reasons for non-completion where appropriate, was emphasized as an integral component for the development of a feasible family caregiver delirium prevention program.

Family caregivers were asked to let the patient’s nurse know when they arrived for the daily visit to support coordination of family caregiver interventions with those of the inpatient team. Instructions for family caregiver implementation of the early mobilization protocol required that family caregivers confirm with the nurse that the older adult patient was able to get out of bed for ambulation and to allow for securing of any tubes and lines. This also allowed for an opportunity to coordinate ambulation with the nurse if additional support was needed. Family caregiver interventions were in
addition to any therapies prescribed by the medical team and not a substitute for recommended treatments. The principal investigator alerted inpatient team members to the older adult patient’s enrollment in the study by placing a notification sheet in the front of the hard copy medical record.

**Study Procedures**

The research study began in July of 2008. An in-service was provided by the principal investigator for the nurses on both study units entitled “Delirium in the Older Hospitalized Adult.” The content included an overview of delirium including the epidemiology, etiology and risk factors, consequences, clinical features, treatment, and preventive interventions. There was a summary of the FPDPP study procedures which entailed no direct care requirements by staff nurses. In addition, there was a review of the previously described supportive nurse behaviors for family participation identified in the pilot study completed by the principal investigator in January of 2008 (see Introduction chapter). Supportive nursing behaviors discussed included: (1) activities aimed at encouraging, where family caregivers derive emotional support from nursing validation of their competence in successful intervention completion; and (2) activities aimed at promoting an uninterrupted environment, with physical support through provision of uninterrupted time for intervention completion. Also in July of 2008, a staff meeting with the Practice Committee on the study unit was held where the study was presented and questions and concerns were addressed. The Practice Committee is composed of physicians, nurse practitioners, and nurses who work on the unit.

In August of 2008, two research assistants, who are advanced practice nursing students in the Acute Care Specialty at the MGH Institute of Health Professions, were
trained in the study protocols by the principal investigator using a standardized Data Collection Manual (see Appendix L). Enrollment of older adult and family caregiver subjects began in September of 2008. Data collection occurred over four months, with enrollment of approximately one to two family caregiver/older adult dyads per week.

Upon enrollment in the study, first, the family caregiver was given detailed instruction in the five intervention protocols by a member of the research team using the Family Caregiver Training Manual (see Appendix J). Family caregivers were instructed on the use of a standardized Family Caregiver Tracking Form (see Appendix K) to record daily frequency of intervention completion and reasons for non-completion. Second, upon discharge of the older hospitalized adult, a questionnaire was distributed to the participating family caregiver (see Appendix M) and the older adult patient (see Appendix N) to explore the facilitators and barriers to family participation in the intervention program. Third, an anonymous, voluntary staff nurse survey was made available daily for 14 days midway through data collection and again for 14 days after subject enrollment was closed to examine nurses’ experience with the intervention program (see Appendix O).

The above methods contributed different and important aspects to understanding of the feasibility of the FPDPP. Self-tracking of completion of assigned intervention protocols, with reasons for non-completion, provided descriptive data on the ability of family caregivers to complete recommended interventions for the targeted risk factors. The family and older adult subject questionnaires were developed to identify barriers and facilitators for participation in the FPDPP, including barriers and facilitators related to the staff nurse. The staff nurse questionnaire contributed important information from the
nursing perspective on their potential role in supporting family caregiver participation to maximize positive outcomes of hospitalization for older adults. These sources provided important information about older adults’, family caregivers’, and nurses’ experiences of participation. This also further established a link between the research study and theoretical framework, the Calgary Family Intervention Model (CFIM). The CFIM consists of three major components: (1) interventions (by the staff nurse); (2) needs of family caregivers; and, (3) the “fit” between them. In this study, these components intersected to impact the outcomes, which included maintenance of cognitive status for the older hospitalized adult and participation in the intervention program by the family caregiver. The CFIM provides the framework for understanding that nursing interventions, which are conceptualized as supportive nursing behaviors identified by both the family caregiver and older adult, promote family participation in the FPDPP.

The principal investigator completed a new Family Caregiver Tracking Form (see Appendix K) daily with assigned intervention protocols based on the older adult’s baseline risk factors. The family caregiver used the form to track intervention completion during the daily visit. The principal investigator retrieved completed logs from the previous day. A binder with each older adult subject’s Patient Care Plan (see Appendix P) with assigned family caregiver interventions was kept at the nurses’ station and updated daily by the principal investigator. This allowed for consistent communication between the researchers and the inpatient team and supported the integration of family caregiver interventions into the plan of care.

The principal investigator screened all enrolled older adult patients daily for the occurrence of delirium. Based on a review of the tracking sheets completed by family
caregivers, intervention completion was monitored on a daily basis. Reasons for non-completion of interventions were addressed whenever possible. Within twenty-four hours of anticipated discharge, the older adult was rescreened by the principal investigator for targeted risk factors for delirium using the previously described assessment tools to compare with admission findings. The family caregiver (see Appendix M) and older adult subjects (see Appendix N) were asked by the principal investigator to complete a questionnaire, which consisted of both Likert scale and open-ended questions on the barriers and facilitators for participation in the FPDPP and supportive nursing behaviors for family participation. An anonymous, voluntary staff nurse questionnaire consisting of both Likert scale and open-ended questions was made available daily for 14 days midway through data collection and again for 14 days after subject enrollment was closed to examine the nurses’ experiences with the intervention program (see Appendix O).

**Measurement**

**Study Variables**

Study variables that were examined include patient and family caregiver demographics; risk factors for delirium (cognitive impairment, ADL impairment, visual impairment, and hearing impairment); delirium; intervention assignment and intervention completion. The older adult patient’s age, gender, race, ethnicity, primary medical diagnosis, and living situation were obtained from the Partner’s Health Care System electronic medical record. Family caregiver demographic data including age, gender, race, ethnicity, level of education, and relationship to the older adult patient were recorded by the family caregiver at the time of consent on the Family Demographic Data
Questionnaire (see Appendix H). These demographic variables were used for descriptive purposes.

In this study, the feasibility of family implementation of a multicomponent intervention protocol is described through a multi-method inductive process using: (1) dual sources of evidence from family caregivers that includes self-tracking of completion of interventions and responding to questions on a questionnaire; (2) evidence from older adult patients responding to questions on a questionnaire; and, (3) evidence from staff nurses responding to questions on a questionnaire. Completion rates (%) by family caregivers to assigned interventions based on the older adult’s baseline risk factors were documented on the Family Caregiver Tracking Form (Appendix K). Consideration of the facilitators and barriers to participation was based on family caregivers’ responses on the Family Caregiver Questionnaire (Appendix M) and older adults’ responses on the Older Adult Patient Questionnaire (Appendix N). This information was augmented with the findings from an anonymous and voluntary Staff Nurse Questionnaire completed by staff nurses on the study unit, which was made available daily for 14 days midway through data collection and again for 14 days after subject enrollment was closed (see Appendix O). The questionnaire was conducted at two points to capture the perspectives of nurses while actively involved in the study in addition to those based on recent memory. Occurrence of delirium was captured daily and at discharge for each older adult patient for descriptive purposes and pilot data for future anticipated work testing the effectiveness of the FPDPP. Study variables and measurements are summarized in Appendix Q.
Older Adult Assessment Methods

Standard clinically meaningful outpoints were used in our assessments of the older adult study subjects. Assessments were completed at admission for the four targeted risk factors for delirium and for the evaluation of competency to sign consent. The occurrence of delirium was assessed at admission, daily, and at discharge. To evaluate the capacity of the newly admitted older adult inpatient to consent to participate in the research study, the Evaluation to Sign Consent (ESC) Measure was used (DeRenzo, Conley, & Love, 1998) (see Appendix G). The screening assessment included the Mini Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975); the Katz Index of Independence in Activities of Daily Living (Katz, Ford, & Maskowitz, 1963); the standard bedside Jaeger test for vision; the Whisper test for hearing (MacPhee, Crowther, & McAlpine, 1988); evaluation by the Confusion Assessment Method (CAM) for delirium (Inouye, van Dyck, Alessi, Balkin, Siegal, & Horwitz, 1990); and, a brief medical record review for the older adult’s medical history. Data collection forms for the standardized assessments (see Appendix L) were based on those used for the HELP program with copyright permission obtained (HELP copyright, 2000; see Appendix I).

Data Analysis

The data analysis plan for the study consisted of two components: Statistical analysis of quantitative data and content analysis procedures.

Statistical Analysis of Quantitative Data

First, the data was cleaned and descriptive statistics were examined for all study variables. Frequency distributions (percentages) and measures of central tendency (modes, medians, means) were calculated to summarize demographic characteristics at
admission for older adult patient and the family caregiver subjects; and to organize the quantitative data related to intervention completion.

Content Analysis

The principal investigator and two graduate research assistants analyzed the family caregivers’, older adults’, and nurses’ responses to open-ended questions using content analysis. The questionnaires for family caregivers, older adults, and staff nurses each involved separate content analysis procedures.

Content analysis refers to a range of tools for analyzing all kinds of text including interview transcriptions and questionnaire data (Franzosi, 2004). The content analysis procedure used in this study is based on Mayring’s (2000) inductive category development and Field and Morse’s (1985) thematic analysis. These types of analyses involve both qualitative and quantitative approaches. Inductive category development is a way of formulating categories that are related closely to the data, without imposing a prior theoretical framework (Mayring, 2000). This required reading through the questionnaires and searching for similarities in responses that could be tentatively grouped together into a category.

Thematic analysis involved developing a coding scheme based on categories. Codes with similar meanings were grouped together as categories and a term, often from the literature, was used to describe them, for example ‘support’. Categories were then drawn together into dominant themes that ran throughout the entire set of questionnaires (Field and Morse, 1985), for example ‘support’ and ‘shared goals’ were grouped together under the theme ‘partnership’. Once dominant themes were captured for each set of questionnaires, further analysis included assessment for common overarching themes.
among those generated from family caregivers’, older adults’, and the staff nurses’ responses.

Specific research questions which were examined are stated, followed by the data analysis strategies used as follows:

*Research Question 1:* Which intervention protocols of the Family Participation Delirium Prevention Program (FPDPP) do family caregivers complete?

Daily and overall completion rates for each intervention protocol were calculated. Descriptive statistics were used to describe the frequency and relative frequency of completion for each of the assigned intervention protocols based on tracking by family caregivers completed on the daily Family Caregiver Tracking form.

*Research Question 2:* How often do family caregivers complete each of the assigned intervention protocols?

Descriptive statistics, including frequencies and relative frequencies, were used to describe how often family caregivers complete each of the assigned intervention protocols relative to the total number of times it was assigned. Graphical summaries, as bar charts, were also produced.

*Research Question 3:* What are the facilitators for family participation in the FPDPP?

*Research Question 4:* What are the barriers to family participation in the FPDPP?

*Research Question 5:* How do nurses facilitate family participation in the FPDPP?

Descriptive statistics were used for responses by family caregivers to Likert scale questions on the Family Caregiver Questionnaire in order to address research questions 3, 4, and 5. In addition, the responses of family caregivers, older adults, and nurses to open-ended questions on the questionnaires were analyzed using content analysis procedures.
The content analysis included the following process completed independently for the family caregiver, older adult, and staff nurse questionnaires:

- Initial thoughts about themes were recorded immediately after reviewing a questionnaire
- The principal investigator and two research assistants read all of the questionnaire responses to become familiar with the data and develop ideas about emerging themes
- Themes were tentatively grouped into categories and the categories were labeled using examples of the subject’s own language
- Clear coding rules and operational definitions were developed by making decisions about inclusion and exclusion criteria for questionnaire responses that reflected family caregivers’, older adults’ or staff nurses’ experiences of participating in the FPDPP following the initial review of the qualitative data. The research team together redefined or discarded codes which were not reflective of the subjects’ experiences of participation based on subjects’ questionnaire responses. The final list of codes represented data on family caregivers’, older adults’ or staff nurses’ experiences of participating in the intervention.
- Checking of coding was accomplished on two occasions where two members of the research team coded the same questionnaire and compared the coding to determine intercoder reliability. Reliability was calculated as number of agreements/total number of agreements + disagreements. It was expected that intercoder reliability would be at a minimum of 80% by the second check.
- Interpretation of the results included counting frequencies in order to make inferences about the relative significance of categories to the subjects.
• Family caregivers and older adult subjects were called by the principal investigator to share study findings and confirm themes generated.

The themes that were consistently supported across all of the family caregiver, older adult, or staff nurse questionnaires are reported. As the data from the questionnaires was analyzed, the research team mapped out the elements that might facilitate implementation of a family protocol for delirium prevention and those that might inhibit implementation. This preliminary evidence will provide data for the future testing of the efficacy of the FPDPP, using the intervention protocols that are feasible for family participation.
CHAPTER 5

RESULTS

Demographics

Patients

Forty-two older adult patients were recruited to participate in the study. Of these, fifteen (36%) met the screening criteria and consented to participate. The demographics of subjects are shown in Table 7.
Table 7: Demographic and Risk Factor Characteristics of Older Adult Patient Subjects

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>(N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sociodemographic</strong></td>
<td></td>
</tr>
<tr>
<td>Age, mean (range; median)</td>
<td>77.8, (68-85; 79)</td>
</tr>
<tr>
<td>Female, n, (%)</td>
<td>10, (60)</td>
</tr>
<tr>
<td>Race, n, (%)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>1, (6.7)</td>
</tr>
<tr>
<td>Black</td>
<td>3, (13.3)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>3, (13.3)</td>
</tr>
<tr>
<td>White</td>
<td>8, (53.3)</td>
</tr>
<tr>
<td>Ethnicity, n, (%)</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>12, (80)</td>
</tr>
<tr>
<td>Living Situation, n, (%)</td>
<td></td>
</tr>
<tr>
<td>Does not live alone</td>
<td>14, (93.3)</td>
</tr>
<tr>
<td>Independence n, (%)</td>
<td></td>
</tr>
<tr>
<td>Lives independently □</td>
<td>10, (66.7)</td>
</tr>
<tr>
<td>Living Children, mean</td>
<td>3</td>
</tr>
<tr>
<td><strong>Risk Factors</strong></td>
<td></td>
</tr>
<tr>
<td>Cognitive impairment</td>
<td></td>
</tr>
<tr>
<td>MMSE score &lt;24, n, (%)</td>
<td>15, (100)</td>
</tr>
<tr>
<td>MMSE score, mean</td>
<td>21.4</td>
</tr>
<tr>
<td>ADL impairment</td>
<td></td>
</tr>
<tr>
<td>Katz ADL Score &lt;10, n, (%)</td>
<td>14, (93.3)</td>
</tr>
<tr>
<td>Katz ADL Score, mean</td>
<td>7.7</td>
</tr>
<tr>
<td>Vision impairment, n, (%)</td>
<td>10, (60)</td>
</tr>
<tr>
<td>Hearing impairment, n, (%)</td>
<td>10, (60)</td>
</tr>
<tr>
<td>Whisper score, mean (uncovered) ζ</td>
<td>6.6</td>
</tr>
<tr>
<td>Whisper score, mean (covered) λ</td>
<td>5.3</td>
</tr>
<tr>
<td>Admitting Diagnosis, n, (%)</td>
<td></td>
</tr>
<tr>
<td>Anemia</td>
<td>1, (6.7)</td>
</tr>
<tr>
<td>Angina, chest pain</td>
<td>2, (13.3)</td>
</tr>
<tr>
<td>Atrial fibrillation</td>
<td>1, (6.7)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>2, (13.3)</td>
</tr>
<tr>
<td>COPD exacerbation</td>
<td>2, (13.3)</td>
</tr>
<tr>
<td>Dehydration</td>
<td>2, (13.3)</td>
</tr>
<tr>
<td>Hypoglycemia</td>
<td>1, (6.7)</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>1, (6.7)</td>
</tr>
<tr>
<td>Renal failure</td>
<td>2, (13.3)</td>
</tr>
<tr>
<td>Wound infection</td>
<td>1, (6.7)</td>
</tr>
</tbody>
</table>

□ Lives independently denotes no help required for activities of daily living including eating, dressing, walking, grooming, bathing, toileting  
ζ Whisper score, mean, testing with researcher’s mouth uncovered
λ Whisper score, mean, testing with researcher’s mouth covered
The mean age of the 15 subjects was 77.8 (range 68-85; median 79) (see Figure 1). Sixty-seven percent of patients were female (n=10) as shown in Figure 2. The majority of patients were White (n=8, 53.3%), with Black (n=3, 20%), Hispanic (n=3, 20%), and Asian (n=1, 6.7%) patients comprising the rest. Race and ethnicity findings are shown in Figure 3.
Figure 1. Distribution of Age of Older Adult Patient Subjects

Distribution of Age
n=15 Consenters

<table>
<thead>
<tr>
<th>Years</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>65</td>
<td>2</td>
</tr>
<tr>
<td>70</td>
<td>3</td>
</tr>
<tr>
<td>75</td>
<td>3</td>
</tr>
<tr>
<td>80</td>
<td>7</td>
</tr>
<tr>
<td>85</td>
<td>3</td>
</tr>
</tbody>
</table>
Figure 2. Distribution of Gender of Older Adult Patient Subjects
Figure 3. Distribution of Race of Older Adult Patient Subjects

Distribution of Race
n=15 Consenters

Number

White  Asian  Black  Hispanic

0  2  4  6  8
Admitting diagnoses for patients are listed in Table 8. On average, patients had three living children (see Figure 4). As shown in Figure 5, 93.3% (n=14) of subjects did not live alone and 66.7% (n=10) were independent within their living situation.

Table 8: Admitting Diagnoses of Older Adult Subjects

<table>
<thead>
<tr>
<th>Admitting Diagnosis</th>
<th>Frequency, n, (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Renal Failure</td>
<td>2, (13.3%)</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>2, (13.3%)</td>
</tr>
<tr>
<td>Congestive Heart Failure</td>
<td>2, (13.3%)</td>
</tr>
<tr>
<td>Angina/Chest Pain</td>
<td>2, (13.3%)</td>
</tr>
<tr>
<td>Chronic Obstructive Pulmonary Disease</td>
<td>2, (13.3%)</td>
</tr>
<tr>
<td>Exacerbation</td>
<td>2, (13.3%)</td>
</tr>
<tr>
<td>Anemia</td>
<td>1, (6.7%)</td>
</tr>
<tr>
<td>Atrial Fibrillation</td>
<td>1, (6.7%)</td>
</tr>
<tr>
<td>Hypoglycemia</td>
<td>1, (6.7%)</td>
</tr>
<tr>
<td>Liver Failure</td>
<td>1, (6.7%)</td>
</tr>
<tr>
<td>Wound Infection</td>
<td>1, (6.7%)</td>
</tr>
</tbody>
</table>
Figure 4. Distribution of Number of Children of Older Adult Patient Subjects
Figure 5. Distribution of Older Adult Patient Subjects Living Independently

Distribution Living Independently
n=15 Consenters

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>4</td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
</tr>
</tbody>
</table>
At least one targeted risk factor for delirium was required for enrollment in the study; however, the majority of subjects had more than one risk factor present at baseline screening. Eighty-five percent of older adult patients had at least two of the four targeted risk factors for delirium and 69% had three or four risk factors present. One hundred percent of older adult patients (n=15) had a risk factor of cognitive impairment with an average MMSE of 21.4, well below the criteria of less than 24 considered indicative of cognitive impairment. Ninety-three percent (n=14) had a risk factor of ADL impairment with an average Katz ADL score of 7.7 indicating moderate functional impairment. Sixty percent of patients (n=10) were found to be hearing impaired using the Whisper test in the standard “uncovered” state when the researcher’s mouth was not covered when whispering. The mean Whisper score was 6.6 in the uncovered state, and 5.3 in the covered state when the researcher’s mouth was covered. Sixty percent of subjects (n=10) had a risk factor of vision impairment (See Figure 6.)

**Figure 6. Risk Factors for Delirium in Older Adult Patient Subjects**
Family Caregivers

The demographics of family caregiver subjects are shown in Table 9.

Table 9: Demographic Characteristics of Family Caregiver Subjects

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>(N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sociodemographic</strong></td>
<td></td>
</tr>
<tr>
<td>Age, mean (range; median)</td>
<td>61.2, (30-82; 65)</td>
</tr>
<tr>
<td>Female, n, (%)</td>
<td>11, (73.3)</td>
</tr>
<tr>
<td>Race, n, (%)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>0, (0)</td>
</tr>
<tr>
<td>Black</td>
<td>3, (20)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>3, (20)</td>
</tr>
<tr>
<td>White</td>
<td>9, (80)</td>
</tr>
<tr>
<td>Ethnicity, n, (%)</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>11, (73.3)</td>
</tr>
<tr>
<td>Education, n, (%)</td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>3, (20)</td>
</tr>
<tr>
<td>High school or equivalent</td>
<td>9, (60)</td>
</tr>
<tr>
<td>Some college</td>
<td>2, (13.3)</td>
</tr>
<tr>
<td>College graduate or above</td>
<td>1, (6.7)</td>
</tr>
<tr>
<td>Relationship to patient, n, (%)</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>3, (20)</td>
</tr>
<tr>
<td>Significant other</td>
<td>2, (13.3)</td>
</tr>
<tr>
<td>Adult child</td>
<td>6, (40)</td>
</tr>
<tr>
<td>Other blood relative</td>
<td>4, (26.7)</td>
</tr>
</tbody>
</table>

The mean age of the sample of 15 family caregivers was 61.2 years with a range of age 30 to 82 years depending on the relationship of the caregiver to the older adult patient. Figure 7 summarizes findings related to age of family caregivers.
Figure 7. Distribution of Age of Family Caregiver Subjects
The most frequent relationship of the family caregiver to the older adult patient was as an adult child (n=6, 40%), followed by other blood relative (n=4, 26.7%), spouse (n=3, 20%), and significant other (n=2, 13.3%) (see Figure 8). The majority of family caregivers were female (n=11, 73.3%) (see Figure 9). Family caregivers were predominately White (n=9, 60%), followed by Black (n=3, 20%) and Hispanic (n=3, 20%). Figure 10 summarizes race findings of family caregivers. Eighty percent (n=12) of family caregivers had completed at least a high school degree and 20% (n=3) had attended or graduated from college (see Figure 11).

**Figure 8. Relationships of Family Caregiver Subjects to Older Adult Patients**
Figure 9. Distribution of Gender of Family Caregiver Subjects

Figure 10. Distribution of Race of Family Caregiver Subjects
Figure 11. Education Completed By Family Caregiver Subjects

Distribution of Education Completed

n=15 Care Givers

Less than HS  |  HS/equiv  |  Some College  |  College +  
0  |  9  |  2  |  1  
Number
**Intervention Protocols of the FPDPP Completed By Family Caregivers**

Over the course of the study, overall intervention completion documented by family caregivers was highest for the orientation protocol (83.5%), followed closely by the vision protocol (81.5%), therapeutic activities protocol (76.9%) and hearing protocol (73.6%). The lowest overall completion rate was for the early mobilization protocol (55.3%). Intervention completion is compared among the five protocols in Figure 12.

**Figure 12. Overall Completion of the Five Intervention Protocols of the FPDPP**

\begin{figure}
\centering
\includegraphics[width=\textwidth]{figure12.png}
\caption{Overall Completion of the Five Intervention Protocols of the FPDPP}
\end{figure}

On the Family Caregiver Questionnaire (see Appendix H), 93% of family caregivers (n=13) indicated that both the orientation and therapeutic activities protocols were “not at all difficult” to perform and 86% (n=12) indicated the vision protocol was “not at all difficult” to complete. The majority (71.4%, n=10) rated the hearing protocol as “slightly difficult” to complete. Fifty seven percent indicated the early mobilization
protocol was “moderately difficult” to perform. No scores of “to a great extent difficult” were given by any of the subjects for any of the protocols.

**Frequency of Completion of Assigned Intervention Protocols By Family Caregivers**

Figure 13 displays overall intervention completion rates for each of the protocols of the FPDPP in relation to the number of times the protocol was assigned. As cognitive impairment was a baseline risk factor for 100% of older adult subjects, the orientation and therapeutic activities protocols were assigned most frequently (91 times each) during the course of the study. ADL impairment was a baseline risk factor for 90% of older adults, therefore the early mobilization protocol was also assigned with a high frequency (85 times). Vision impairment and hearing impairment, which were each a baseline risk factor for 60% of older adult subjects, were assigned less frequently (54 and 53 times respectively).

**Figure 13. Overall Intervention Completion Rates In Relation To Times Assigned**
Barriers for Family Participation in the FPDPP

Dominant themes were captured for the questionnaires given to family caregivers subjects at discharge. Three themes encompassing barriers to participation in the FPDPP were identified (see Table 10). Each theme is discussed in turn, and quotes from the family caregivers are used to illustrate analytic arguments. Conditions which acted as barriers were subsumed under three themes: the rapid pace of the acute care environment; the older adult’s compromised physical state; and fear. Each presented a unique challenge for family caregivers to successfully complete FPDPP interventions.

Table 10: Three Themes On Barriers for Family Caregiver Participation

<table>
<thead>
<tr>
<th>THEME</th>
<th>Frequency, n (%)</th>
<th>ζ</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The Rapid Pace of the Acute Care Environment</td>
<td>14, (100)</td>
<td>N=14</td>
</tr>
<tr>
<td>2. The Older Adult’s Acutely Ill State</td>
<td>12, (85.7)</td>
<td></td>
</tr>
<tr>
<td>3. Fear</td>
<td>12, (85.7)</td>
<td></td>
</tr>
</tbody>
</table>

ζ Frequency refers to how often the dominant themes were found on questionnaires

The Rapid Pace of the Acute Care Environment

Family caregivers noted that the frenetic pace of the acute care environment presented a challenge to successful intervention completion. Frequent interruptions, noise, and lack of privacy were identified as major barriers.

My wife and I were trying to read the newspaper out loud together. The noise coming from outside in the hall drowned us both out. It was too loud and too cramped for me to even carry on a conversation more than a few seconds. I wish that there was more privacy and noise control so that she and I could have an opportunity to play the games in a more calming environment.
The Older Adult’s Acutely Ill State

Family caregivers identified symptoms of pain, shortness of breath, fatigue, and nausea experienced by the older adult patient that interfered with participation and thus intervention completion.

Mom was exhausted. Even listening to her favorite 1930’s tunes didn’t help. I felt like a bully trying to get her to walk when she was so weak. The exercises in bed weren’t much better. She had a lot of pain related to the infection and I felt horrible subjecting her to more by moving her legs.

Fear

Caregivers expressed feeling ill-prepared to engage in activities with their acutely ill family member, especially the early mobilization interventions.

Even though the nurse told me it was okay, I still felt scared to walk with Mom because she was so weak.

All that my sister wanted to do was rest. I was afraid to push her because I didn’t want to make her heart problem worse.

Facilitators for Family Participation in the FPDPP

Family caregivers identified the conditions that were most important for supporting participation in the FPDPP. Support activities were subsumed under three themes: therapeutic relationships, uninterrupted time, and educational reinforcement (see Table 11).

Table 11: Three Themes On Facilitators for Family Caregiver Participation

<table>
<thead>
<tr>
<th>THEME</th>
<th>n, (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutic Relationships</td>
<td>14, (100)</td>
</tr>
<tr>
<td>Uninterrupted Time</td>
<td>14, (100)</td>
</tr>
<tr>
<td>Educational Reinforcement</td>
<td>12, (85.7)</td>
</tr>
</tbody>
</table>
**Therapeutic Relationships**

Family caregivers identified a therapeutic relationship with the staff nurse caring for their older adult family member as key to successful participation. Knowing that the staff nurse was willing to offer nonjudgmental support, reassurance, and positive reinforcement provided great comfort during a stressful time. Family caregivers shared the following experiences:

I felt that because I had seen and spoken to the nurse early on that we were able to make a plan for my mother’s care needs and her treatment; not just for the chest infection, but for her need to maintain routine with her daily tea and newspaper.

I started the whole program nervous about failing, not being able to do the things I said I would. One of the nurses came and sat on the bed because she realized I was upset. She took the time to listen to me, to answer my questions. I no longer felt I was alone in the burden of keeping my husband safe.

Family caregivers derived emotional support from validation by staff nurses of their competence in successful intervention completion.

The nurse would greet me with a smile and complement me for a job well done. I trusted her. This was key for me to keep trying with the program; key to me feeling like I was making a difference.

**Uninterrupted Time**

Family caregivers identified the provision of uninterrupted time for intervention completion as important for successful participation. When nurses clustered their care activities for the older adult patient and minimized unnecessary interruptions, family caregivers were given the time and privacy required for participation. The family caregivers who valued uninterrupted time commented:

My wife’s nurses knew I was participating in the program so, as much as possible, the nurses limited unimportant interruptions during my visits. I would let them know when I arrived and the nurse would just check in on us periodically or if we needed something.
The unit was very busy in the morning when most of the blood tests, x-rays, and exams were done. So I decided to visit and do the programs when I was finished at work. Five-thirty was a perfect time. We could have a “more” quiet dinner together, review the day’s events, and read together. It helped too because usually Mom’s nurse had been with her all day, so she really knew what was going on with her.

Uninterrupted time was key. On those days that my husband wasn’t being carted off to a test when I was there, I was much better able to do the program activities.

**Educational Reinforcement**

When staff nurses reinforced the teaching provided in the educational training for the FPDPP, family caregivers noted that they were more likely to successfully complete interventions. A family caregiver commented on the benefits of continuing support and learning:

> I think what made it the easiest was the initial training followed by the daily contact with the nurses and the researchers to clarify issues and keep the ball rolling.

Another family caregiver echoed:

> It takes a little time and effort to do all of the protocols and to really think about them. Although I got better each day, reminders were much appreciated.

**The Role of Nurses in Facilitating Family Participation in the FPDPP**

Thirty-eight of the 64 staff nurses employed on the study unit completed an anonymous Staff Nurse Questionnaire with a response rate of 59.4%. Twenty-one questionnaires were completed during a two week period at the half way point of data collection. Seventeen additional questionnaires were completed during a two week period after data collection was closed.

Dominant themes were captured for the questionnaires. Five themes which address the role of staff nurses in family participation in the FPDPP emerged from the responses of staff nurses (see Table 12). Two themes address barriers to family
participation and two themes describe facilitators for family participation. An additional theme encompasses the important role of the nurse in determining to intervene where nurses describe how they identify patients at risk for delirium and involve the family in preventive interventions.

**Table 12: Five Themes on the Role of the Staff Nurse in Participation in the FPDPP (N=38)**

<table>
<thead>
<tr>
<th>Barriers</th>
<th>n, (%)</th>
<th>Facilitators</th>
<th>n, (%)</th>
<th>Determining To Intervene With Preventive Interventions</th>
<th>n, (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of Family Caregiver Collaboration</td>
<td>32, (84.2)</td>
<td>Family Collaboration</td>
<td>32, (84.2)</td>
<td>Risk Factor Identification</td>
<td>29, (76.3)</td>
</tr>
<tr>
<td>Lack of Time</td>
<td>38, (100)</td>
<td>Seeing the Intervention Program as a Challenge</td>
<td>30, (79)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Barriers**

**Lack of Family Caregiver Collaboration**

As nurses described their role in supporting the family caregivers in participating in the FPDPP, the difficulty with the early mobilization and hearing protocols was noted. This was largely attributed to lack of family caregiver collaboration. Nurses described their experiences with attempting to facilitate the participation of family caregivers in completing both the early mobilization and hearing protocols:

I tried to reassure the patient’s wife that we had been getting him out of bed every four hours and walking around the unit at least twice. I told her that he had been doing this for days and I would help her if needed. She did not want to do this without a physical therapist present despite my reassurance that we had been doing it for days without help.
We never got the patient’s daughter to bring in her Mom’s hearing aids. She went through the family caregiver training and had the manual explaining how the hearing protocol activities depended on this. We tried to encourage her, but we couldn’t get family caregiver cooperation.

The patient’s daughter was doing a great job ambulating with her dad whenever she visited for the first few days. Then he needed a Foley catheter as he was having difficulty voiding. I reassured her that he could still walk with the Foley catheter and even helped her the first few times. But she was frightened to do it alone. She just couldn’t do it because she was so scared.

**Lack of Time**

While the process of using the FPDPP protocols was deemed useful, the lack of time available to do so successfully was identified as a barrier. Staff nurses noted that the regulatory environment of acute inpatient care and financial constraints experienced in these settings has lead to tremendous amounts of documentation – and there often exists limited staff to complete this work. Nurses described how the time factor impacted their ability to participate in the FPDPP and having limited time to engage with families:

I think to do the older adult patient and the family caregiver credit and provide a service to them, you have to be consistent and available. But do we have the time and energy? No.

I’m sure this happens at other hospitals too….We are distracted by other things we have to do. We would get interrupted for a time when the family caregiver was trying to ask us questions. They would have to wait for awhile and we would come back to it later. Often the family caregiver had left. It would have been nice if we could have sat there when the request for support was made without any distractions or interruptions, but on our unit this is quite difficult.

What is the most difficult part of participating in the FPDPP? I would say time – not having time to support the family members, to educate them- and time to sit down and reinforce their helpful efforts.
Facilitators

Family Collaboration

Staff nurses noted that collaborative efforts between the nurse and the family caregiver can positively affect participation in the FPDPP. The nurse, through the systematic use of this intervention program, may determine that an older adult is delirious or has risk factors for delirium. Through open communication and effective collaboration with involved family, staff nurses believed the best outcome for the older adult could be achieved:

When the family caregiver came in, we were reviewing the care plan for her husband in the delirium program, and I went back and showed it to them. I said ‘this is what we could be doing so he does not get confused while he is here in the hospital.’ The family caregiver found this very interesting as these were things she was used to doing at home, therefore could easily do while her husband was here. She did do these things while he was here, let me know they were done, and her husband did not get confused despite all his risk factors. The thing is – you need to have a family caregiver who is willing to sit down, review the protocols with the nurse, and actually do them. This was a loving family caregiver.

Seeing the Intervention Program as a Challenge

Based on their prior personal and professional experiences, staff nurses viewed participating in the FPDPP as either a burden or as a challenge. In general, staff nurses agreed that when the responsibility was seen as a challenge that the care provided would more likely positively impact the older adult. One nurse described:

I think you have to get a nurse that really would want to be involved in this type of intervention program and seeing it as a challenge, really wanting to work with the families and appreciating their potential impact, and not see it as a meaningless task or burden. You need people who are willing to take the time to go through the process of working with families, rather than just see it as another routine task.
Another nurse reflected:

I noticed some nurses who were really involved….and others who were not. You have people who jump on the bandwagon and say, ‘oh yeah, I’m all for seeing if we can improve this’ and others who are just not interested. I feel like those nurses who rose to the challenge of learning about new ways of thinking and clinical practice had the best chance of having a powerful impact on the patients’ and families’ experience of care.

**Determining To Intervene With Preventive Interventions**

The nurses in this study described their decision making process on determining what risk factors for delirium in the older hospitalized adult require preventive intervention. Staff nurses identified the risk factors that aided the nurse in determining to intervene with preventive interventions. The risk factors fell within three categories: (1) the older adult demonstrates a behavior outside their norm or signaling some type of discomfort; (2) the older adult is deconditioned and has experienced a decline in physical strength; and, (3) the older adult is in an unfamiliar environment. For example, several nurses described observing a change in behavior or functioning that triggered the nurse’s attention:

A red flag includes changes in behavior and changes in mood from what the family reports or what I observed on admission. Sometimes it is becoming withdrawn – that’s a big one.

Another nurse stated:

It depends on what the risk factors are and the person, what the impact is on them, and what the impact is on others. I see the impact on the patient, the impact on the nurses caring for him or her, and the impact on the caregivers. You have to look at the whole circle of people involved. I think that’s the biggest thing.

Determining to intervene with preventive interventions, based on how significant an older adult’s risk factors are, was described by several nurses. The deciding factor that aids in determining whether to intervene is whether there is possibility for harm - to
themselves, to others including family members, and to the nursing staff – or how much the staff complains:

I think specifically when an older adult needs preventive intervention is when they are acting ‘differently’ than typically with family members. I always try to respect the family’s experiences of knowing the older adult patient.

Being extremely withdrawn with no affect is always a worry. If someone shows little emotion in response to the stress of hospitalization, I try to figure out if this is their normal coping style, a little depression, or heralding some kind of change in mental status.

Twenty-nine of the 38 nurses (76.3%) who completed the staff nurse questionnaire described risk factor identification as a key motivator for eliciting family involvement in the older adult’s care. For older adult patients deemed at risk by the staff nurse and who had a family caregiver already enrolled in the FPDPP, nurses noted the implementation of many of the preventive interventions they were aware of from the literature and from their experience caring for this population. A staff nurse shared:

The 86 year old patient I had cared for numerous times over the past year developed a urinary tract infection while she was on our unit. She normally was sharp as a tack but I was worried this would throw her for a loop. I went in to assess her. Her daughter was already at the bedside and they were reading the newspaper together. She was wearing her glasses which were brought from home. Her daughter was two steps ahead of me. She told me she was participating in the program and we reviewed the manual together.

Another nurse noted:

I always call the family as soon as possible when I see risk factors for confusion or subtle changes in my older adult patients. I used to work in a nursing home and we got the family involved early on so it was ingrained as a habit. Still here in the hospital, if I find out on admission assessment the patient wears hearing aids I call to have a family member bring them in. I did notice the two patients who I cared for that were involved in this study had a consistent caregiver at the bedside who was intervening in a way that my patient assignment often does not allow for.
Staff nurses noted that whether by virtue of participating formally in the FPDPP or being present in response to a phone call from the nurse, family caregivers who were involved at the bedside in the older adult patient’s care made important contributions toward prevention.

**Overarching Themes**

Questionnaires given to family caregivers and older adults at the time of discharge, and to staff nurses at the midpoint and at completion of the study revealed three common overarching themes related to participation in the FPDPP: partnership, therapeutic relationships, and environment. The three themes and the categories within each, derived from a total of 67 questionnaires, are shown in Table 13. Eighty four percent of questionnaires (n=56) contained responses encompassing the theme of therapeutic relationships, while 82% (n=55) contained responses encompassing the theme of partnership. The theme of environment in relation to participation in the FPDPP was found in 75% (n=50) of questionnaires.

**Table 13: The Three Overarching Themes Drawn From Family Caregivers’, Older Adult Patients’, and Nurses’ Responses and Their Categories N=67**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Partnership</th>
<th>Therapeutic Relationships</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Categories</td>
<td>Respect</td>
<td>Connecting with the person</td>
<td>Physical space</td>
</tr>
<tr>
<td>Trust</td>
<td></td>
<td>Time</td>
<td></td>
</tr>
<tr>
<td>Negotiation</td>
<td></td>
<td>Support</td>
<td>Privacy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Staff numbers</td>
</tr>
</tbody>
</table>

**Partnership**

Partnership involved the process of developing relationships between the nurse and the older adult patient and their family caregiver that could form the basis for
participation in the FPDPP. Within this theme there were three categories: respect, trust, and negotiation. Respect and trust were seen as underlying beliefs upon which partnership should be based.

Negotiating participation in the FPDPP could be challenging and involved a continuous, dynamic process of communication, evaluation, and change. One example of this process concerned an older adult patient who wished to have some control over how his care was structured. Because he had a risk factor of hearing impairment, he was assigned to participate in the hearing protocol with his family caregiver. As he rarely wore his hearing aids at home, the patient was extremely upset when his wife brought them in and requested that he wear them. The nurse then went in to talk to the older adult and recounted:

I went to my patient and bluntly said ‘Look, you should wear your hearing aids. The doctors, nurses, and your wife all want to make sure you can hear us.’ And then he got very angry and distressed – he said he had his ‘rights’ and that he was an expert lip-reader, and that he wife never demanded that he wear them in his home. So after awhile, I realized I shouldn’t have done that.

On reflection, the nurse realized that assumptions had been made. Using a different approach, the nurse and family caregiver focused on the strategies within the hearing protocol that supported lip-reading by the patient. A good working relationship was established based on the understanding that was gained from this incident. Once the older adult appreciated that negotiation had occurred, respect and trust were rebuilt to support a partnership for participation in the FPDPP. Learning to deal with the emotions engendered by negotiation and reflecting on the experience were seen as good opportunities for learning. In this incident, the nurse felt that the patient had challenged her attitude and this helped to change the way she approached older adult patients.
Therapeutic Relationships

There were three categories within the theme of therapeutic relationships: connecting with the person, time, and support. The theme of therapeutic relationships was concerned with making connections - between the nurse and patient and between the nurse and family caregiver – in addition to the time required for these connections to be established and support to be experienced. Patients and family caregivers noted that in situations where the nurse offered both the family caregiver and the patient time for teaching, time for questions, and time for establishing a partnership, the foundation of a therapeutic relationship was established. The support component was integral to continued participation in the FPDPP. An older adult patient shared:

It wasn’t until I had been in the hospital for about 24 hours and my wife and I had agreed to be in the study that the nurse came and sat on the bed because she realized I was upset. She took the time to speak with us, calmed my wife’s nerves about walking with me when I was ill. She shared with us how her own mom had recently been in the hospital, and even though she was a nurse, she too was afraid to help her engage in her usual activities because she was so sick. I felt like we were talking human to human, person to person, instead of being told what to do. Her reassurance and encouragement was based not only on her ‘book smarts’ but also her own life experience. My wife and I now felt we had an ally in the whole impersonal hospital environment.

A nurse shared a similar sentiment:

The time I spent answering the questions of my patient’s son related to the program was well spent. Besides clarifying any difficulties he had with the protocols, I could encourage him for those that he completed. It felt good that anytime I took care of his mom, he would seek me out to check in.

When a connection, time and support were not experienced in the context of the nurse/patient/family caregiver relationship, participation in the FPDPP became much more of a challenge for all three groups of subjects:
I wanted the nurse to help me change the batteries for my hearing aid so I could do the hearing activities with my wife when she came to visit. She gave me my medicine without even acknowledging that I asked.

I tried to get my wife to get out of bed and walk with me, but she was too tired. When I asked for help from the nurse, she said she was too busy, ‘Maybe later’, but she never came back.

I did not feel obligated to answer the family’s questions regarding the program. They completed training and had a manual that was self explanatory.

**Environment**

The key element that runs through the theme of environment is the importance of supporting a physical environment that empowers patients and families to participate in the plan of care. There were three categories in this theme: physical space, privacy, and staff numbers. Family caregivers focused on having adequate physical space, privacy, and access to the nursing staff as integral to their successful completion of interventions. Older adults similarly identified “having room to move,” quiet time, and available staff familiar with their care as facilitating participation. For example, an older adult patient and his family caregiver echoed a similar sentiment with identification of analogous factors that enabled participation. The family caregiver shared the following:

The most important thing for my father and me to get through all the activities was what the hospital environment was like that day. On the days that he had a room to himself, when we weren’t constantly interrupted, and when I could find the nurse to ask her questions, my father was ready to participate and I was able to complete all the activities. Otherwise it was much more difficult.

Staff nurses identified comparable conditions in the environment to those identified by both family caregivers and older adult patients that supported participation in the FPDPP. Here nurses describe their experiences of the hospital environment as it enabled participation to take place:
The family caregivers and patients who had the easiest time with the program were not inhibited by conditions such as ‘tight quarters.’ The patient was usually a more medically stable one who did not need frequent monitoring, labs, or testing.

When we were adequately staffed, I felt like I could maximize the patient and family caregiver’s potential for participation. I was more able to cluster care thus minimizing interruptions and could allow them the quiet time they needed while still being accessible.

For family caregivers, older adult patients, and the staff nurses who provided care for them, the nature of the environment on the unit was realized as an essential component of successful participation.
CHAPTER 6

DISCUSSION

The results of this study support the feasibility of family participation in a delirium prevention program for the older hospitalized adult and provide further support for the use of the Calgary Family Intervention Model to guide delirium prevention efforts. Based on the completion rates of assigned interventions by family caregivers, it appears that the FPDPP is feasible for implementation in the acute care setting. The orientation, therapeutic activities, vision, and hearing protocols were each completed by family caregivers at least 75% of the time. The early mobilization protocol, which presented the biggest challenge for family caregivers to complete, was completed just over 50% of the time. A remarkable level of agreement was found on the concept of the feasibility of family participation among older adult patients, family caregivers, and staff nurses with the common themes that emerged. Although the program does appear to be feasible, key to its successful implementation in future studies or outside of a research setting will be incorporation of the facilitators for participation identified by subjects and implementation of strategies to minimize the barriers to participation.

The Calgary Family Intervention Model (CFIM) as a family nursing intervention model appreciates that openness to certain interventions is profoundly influenced by the relationship between the patient, nurse, and family (Bohn, Wright, & Moules, 2003; Duhamel & Talbot, 2004; Leahey & Harper-Jacques, 1996), and provides a framework for understanding how nurses in this study could support family caregivers’ participation in the Family Participation Delirium Prevention Program (FPDPP) through a partnership.
This study was based on the assumption of the CFIM that family participation is influenced by the relationship between the patient, nurse, and family.

The facilitators and barriers that emerged from the perspectives of older adult patients, family caregivers, and staff nurses in this study were generally consistent with the concept of family-centered care as described in the literature (Leahey, 1987; Wright & Leahey, 1987). As an overall philosophical approach to patient care, family-centered care empowers patients and their families through effective help-giving (Dunst & Trivette, 1996). For example, because of their proximity to both the patient and family, nurses are often the principal providers of ongoing emotional and psychological support to family caregivers. Nurses who are responsive to family cues for support and who are approachable have been found to consistently provide effective support (Boykoff, 2006; Weller & Miller, 2007). Studies have identified strategies that enhance nurse-family partnerships which include spending time with patients and families, showing empathy, respecting family opinions, supporting a non-hurried environment, and willingly explaining procedures and treatments (Boykoff, 2006; Hupcey, 2008). A systematic review of 31 family care studies found that when staff facilitate the communication of family members’ needs by promoting expression of fears, concerns, and feelings, family members’ distress diminishes (Rutledge, Donaldson, & Pravikoff, 2000).

These existing research-based findings highlight the important components of family-centered care including the significance of the relationship between the nurse and the family. The findings of this study are consistent with this family-centered philosophy of care as supported by the themes of therapeutic relationships, partnership, and environment that emerged as key facilitators of family participation. Family caregiver
subjects identified a major key to successful participation as the presence of staff nurses who approached families collaboratively and intervened by fostering their active participation in caregiving and decision making. When the climate supported family engagement and collaboration, which is the foundation of family-centered care, participation occurred and the foundation of a therapeutic relationship was established.

Based on the thematic findings of this study, facilitators and barriers to participation in the FPDPP were clustered into the overarching themes of partnership, therapeutic relationships and environment as outlined in Table 14. To give an example, through developing understanding in working closely with the patient and family in a partnership, listening and being present to establish a therapeutic relationship, and supporting a calm unhurried environment, staff nurses created opportunities for family caregivers’ participation in the FPDPP.

**Table 14: Themes on Facilitators and Barriers to Participation in the FPDPP**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Facilitator</th>
<th>Barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partnership</td>
<td>Respect</td>
<td>Lack of respect for patients and families</td>
</tr>
<tr>
<td></td>
<td>Trust</td>
<td>Poor follow through</td>
</tr>
<tr>
<td></td>
<td>Negotiation</td>
<td>Inflexibility</td>
</tr>
<tr>
<td>Therapeutic Relationships</td>
<td>Connecting with the person</td>
<td>Poor listening</td>
</tr>
<tr>
<td></td>
<td>Time</td>
<td>Distractions</td>
</tr>
<tr>
<td></td>
<td>Support</td>
<td>Not being responsive to patient and family needs</td>
</tr>
<tr>
<td>Environment</td>
<td>Adequate physical space</td>
<td>Close quarters</td>
</tr>
<tr>
<td></td>
<td>Privacy</td>
<td>Frequent interruptions</td>
</tr>
<tr>
<td></td>
<td>Adequate staffing</td>
<td>Staff shortages</td>
</tr>
</tbody>
</table>
The subjects in this study identified the major factors that can facilitate participation in a delirium prevention program for older hospitalized adults, both generally and specifically, in the context of the acute care environment. Subjects stressed that relationships are central to almost all facilitators. Patient and family members reported that respect, trust, and positive negotiation were facilitators for their participation. From the responses of family caregivers, it became obvious that the development of a therapeutic relationship based on a partnership between the family caregiver and the nurse impacted not only the well-being of the older adult patient, but also the emotional well-being, and consequently the continuation of the caring role, of the caregiver. When an older adult patient becomes confused, the emotional effects on his or her physical recuperation begin to have an effect on outcomes, such as increased chance of institutional care and loss of skills, which subsequently increases the ‘burden’ on the caregiver.

Several processes were described as important for therapeutic relationships: connecting with the person, listening, adequate time, and feeling supported. Older adult patients and family caregivers noted that in situations where the nurse offered time for teaching, time for questions, and time for establishing a partnership, the foundation of a therapeutic relationship was established. When a new program or method is taught, there is a need for continuing feedback and clarification. That subsequent successful implementation of the learned process will follow is not necessarily true. Family caregivers noted that participation was facilitated when staff nurses were available as resources for educational reinforcement of the interventions of the FPDPP and were accessible for additional support if needed.
Similarly, family caregivers and patients valued the emotional support that was provided during the time spent with the nurses. The support component was integral to continued participation in the FPDPP. Developing a supportive relationship with the family caregiver as well as the older adult patient ensures that the wellbeing of the older adult is at the forefront of care benefitting both the patient and family. Opportunities for family caregivers and older adult patients to express their concerns and feel understood contributed to their experience of developing a therapeutic relationship with the nurse. It was when a therapeutic relationship was established that family caregivers described “no longer feeling alone” in the burden of keeping their loved ones safe.

In this study, partnership focused on the beliefs and values that underpin the relationships between nurses, patients, and family caregivers, and how these beliefs and values were carried through in negotiations with patients and families. Respect for the person, regardless of their condition or behavior, was highly valued. Trust was also important for participation in the FPDPP and needed to be present between nurses and patients and between nurses and family caregivers for a partnership to occur. Both trust and respect were dynamic concepts, and needed constant negotiation as the nature of the relationships changed. Staff nurse participants repeatedly identified the need for nurses to have in-depth knowledge of the older adult patient’s and family’s needs, in addition to communication skills that foster positive interactions, in order to establish therapeutic relationships. Facilitating both patients' and family caregivers’ control over their own activities related to the FPDPP was a key aspect of partnership. This was related to the importance of creating opportunities for patients and family caregivers to be involved actively in the plan of care.
 Older adult patients, family caregivers, and staff nurses alike frequently emphasized the importance of the environment in facilitating participation. They stressed that participation in the FPDPP requires an environment with adequate space and room to move safely, minimized distractions and interruptions, and available nursing staff to support success. Older adults and family caregivers believed it was the quality, not necessarily the quantity, of time spent interacting with staff nurses that really mattered. However, staff nurses often expressed concern over the lack of time for meaningful interactions with patients and families due to the increasingly rapid pace and high acuity of the inpatient environment.

The major barriers to participation in the FPDPP identified by older adults, their family caregivers, and the staff nurses caring for them are simply the absence of facilitating factors. Logistical factors most often posed barriers to participation in the FPDPP including the organization, delivery, and environment of acute medical care. The key element that runs through the theme of environment is the importance of supporting an environment that empowers patients and families to participate in the plan of care. This theme reflects the difficulty of promoting participation within the constraints of the rapid pace and high acuity of the acute care environment. Staff nurses also emphasized the importance of the patient’s and family caregiver’s experience of the relationship with the staff nurse. They observed that a negative interaction with a staff nurse sets the patient and family caregiver up to have a negative overall experience of hospitalization as nurses are at the forefront of direct patient care.

In this study, the facilitators and barriers for participation were noted to have an important impact on successful completion of the early mobilization protocol. The lack of
family caregiver collaboration identified by staff nurses as a barrier to participation was in truth due to factors around the older adult’s physical state and the nature of the acute care environment which presented the biggest challenge for subjects. Symptoms of pain, shortness of breath, fatigue, and nausea were identified as a common factors interfering with the older adult’s participation in mobilization activities. Family caregivers experienced fear and feeling ill-prepared to engage in these activities with their acutely ill family member. The rapid pace of the acute care environment frequently did not allow staff nurses time to support family caregivers when they experienced concern about performing early mobilization activities when the older adult patient was in a frail, deconditioned, or compromised state.

For the 55% of times the early mobilization protocol was completed when assigned, facilitators included activities which are encompassed in the overarching themes of partnership, therapeutic relationships, and environment that emerged in this study. When concerns about the early mobilization activities were experienced, family caregivers identified the integral role of the staff nurses in supporting successful completion. One of the ways the nurses supported successful completion was when reassurance and education around the mobilization protocols were provided to the patient and family. In addition, opportunities for both older adults and family caregivers to express their fears about participating in the early mobilization activities and feel understood contributed to their deriving confidence in the safety and utility of the early mobilization protocol. When the environment supported uninterrupted time to have questions answered, subjects felt empowered to undertake the challenge that they perceived to be associated with ambulation activities. Continuing feedback and
clarification from staff nurses allowed both patients and family caregivers to develop increased autonomy in completing the early mobilization activities.

When nurses developed a therapeutic relationship with the family caregiver as well as the older adult patient as a partnership, the wellbeing of the older adult remained at the forefront of care. The importance of this relationship is underpinned by the assumption of the CFIM that family participation may be influenced by the relationship between the nurse and the family. The CFIM provides a framework for understanding how nurses can support family caregivers’ participation in a multicomponent intervention program for delirium prevention in the older hospitalized adult which in this study was identified by family caregivers as a therapeutic relationship based on a partnership.

Nurses also acknowledged that patients and family caregivers brought their own set of facilitators and barriers to participation in the FPDPP. Patient and family caregiver subjects emphasized, and staff nurses agreed, that the patient and family caregiver bear the central responsibility for participation. However, when this responsibility was supported by the staff nurse, there was increased likelihood of successful participation.

**Family-Centered Care**

Family-centered care is grounded by the assumption that health care professionals alone do not and cannot know what is best for patients. Critical components of family-centered care include: (1) respecting the focal role of the family; (2) developing plans of care based on partnerships and collaboration between family members and health care professionals; (3) continual sharing of truthful and accurate information with family members; (4) acknowledging the stressful nature of hospitalization for both patient and family; and (5) implementing policies and programs
that are designed to meet family needs (Hostler, 1999; Rushton, 1990; Shelton & Stepanek, 2004). The CFIM has been used extensively as the conceptual framework for studies operating on the assumptions of a family-centered care philosophy and to test interventions that involve the patient and family to improve outcomes of care (Addington, Collins, McCleery, & Addington, 2005; Martin-Arafeh, Watson, & Baird, 1999; Riley-Doucet, 2005; Simpson, Yeung, Kwan, Wah, 2006). The facilitators and barriers that emerged from the perspectives of the older adult patients, family caregivers, and staff nurses in this study were generally consistent with the concept of family-centered care as described in the literature (Leahey, 1987; Wright & Leahey, 1987).

Families of hospitalized patients have reported intense distress, anguish, and role disruption related to hospital experiences (Titler, Cohen, & Craft, 2001). Altered communication among family members, along with the feeling of threat posed by illness, its treatment, or complications, are common themes underlying family concerns when hospitalization of a loved one occurs. Many times in America’s patient-centered health care system, family needs are inadvertently neglected as nurses and the health care team focuses on the pressing needs of the patient. Yet failure to systematically assess and address unresolved issues and concerns of the patient’s family may compromise family members’ capacity for caregiving demanded by illness episodes, ultimately impacting the costs and outcomes of health care. While professional nurses have espoused family-centered care for decades, evidence of its implementation and effect on the patient and family have only recently begun to accumulate in the literature.

There are many assumptions about family caregivers of patients which are important to consider in supporting an environment of family-centered care. First, the
family is part of the patient’s environment for recovery. The family remains constant in the patient’s life while the role of the health care system fluctuates with the patient’s needs and conditions (Jay & Youngblut, 1991). In this study, family caregivers needed to support the sick patient and often needed permission and guidance from the nurse to do this in appropriate ways. Second, family members want ready access to medical and nursing staff and to obtain information and have questions answered in understandable terms (Coulter, 1999; Curry, 2007). When the family caregiver subjects received clear, consistent communication from the staff nurses in this study, participation was facilitated.

Based on patient and family caregiver interviews, nursing input, and the literature, “involvement of family and friends” is one of the seven dimensions that define an optimal model of care delivery (Gerteis, Edgman-Levitan, Daley, & Delbanco, 1993). Families want to be involved in patients’ health care for a number of reasons including: (1) the need for family members to advocate for the patient’s best interest including monitoring the care and participating in decision making; (2) the long term responsibility for families to provide care; (3) the impact of the patient’s illness on the family; and (4) the impact of the family on the patient, his or her health, and the care trajectory (Ellers, 1993). In the short-term, nursing involvement with family caregivers of patients in acute care settings can facilitate favorable clinical outcomes as family caregivers can influence the patient’s immediate recovery. Over the long run, nursing involvement with family caregivers during hospitalization can carry over so that family caregivers can continue to support both treatment and preventive regimens prescribed for the older adult, and as result overall outcomes including morbidity and mortality. Thus, it is in the best interest
of any health care organization to respond to the needs and expectations of patients’ family caregivers.

The results from this study suggest that, in practice, we have not yet adopted a culture of family-centered care where bedside nurses are vested in both patients and their families. In this study, as the assumptions of the CFIM predict, family caregivers noted that when nurses took the time to develop a plan of care that included both the patient and family, the foundation of a therapeutic relationship was established. However, nurses have not universally incorporated the family into patient care for many reasons. The reasons may lie within the nurses themselves or within the patient or family unit (Shelton & Stepanek, 2004).

Challenges to family-centered care in the context of the Family Participation Delirium Prevention Program as implemented in this study can be categorized as organizational and educational. Organizational issues included the rapid pace of the acute care environment and time constraints which often disallowed planning and carrying out family-centered care. An educational challenge described by the staff nurses in this study was minimal formal education on the components of family-centered care and its implementation, a finding which has been previously reported in the literature (Curry, 2007). Nurses sometimes reported providing what they considered to be family-centered care, but patients and their family caregivers frequently disagreed with this conclusion.

**Limitations**

This study was designed to examine the feasibility of family participation in a delirium prevention program for the older hospitalized adult. Limitations include a small,
convenience sample, the requirement of active, daily family participation, and limitations of responses that were due to the nature of the acute care environment. As a result, the findings cannot be generalized outside this setting.

Although the findings may not be generalizable to all patients or settings and the purpose of this study was in fact to examine feasibility of the FPDPP, these findings likely represent the perspectives of many older adult patients, their family caregivers, and the nurses who care for them in the medical inpatient setting. The demographics and primary medical diagnoses of the population on the study unit reflect current medical inpatient trends nationally (Health Care Quality and Cost Information Initiative, 2008). In addition, overall families have been shown to want to be involved in patients’ health care which includes efforts toward prevention (Ellers, 1993). Based on this knowledge, it would appear that many family caregivers of older hospitalized adults are invested in participating in their family member’s plan of care.

The degree to which action and collaboration occurred within this study reflects the limitations of undertaking research in clinical practice areas. The principal investigator is employed by another division of the parent organization, and was therefore an outsider to the unit under study. The nurse manager, clinical nurse specialist and senior staff were involved in development of the proposal and the progress of the research. Initially, a more equal level of collaboration was envisioned with the participation of the head nurse as a resource to support the staff nurses with patients and families enrolled in the study. However, the head nurse left her position early in the study. Due to staff commitments and changes on the unit, organizational support for collaboration was limited. Leadership has been identified as an essential element in the
process of participation (McCormack et al., 2002). Relying solely on an external researcher, therefore, limited the degree of collaboration and participation achieved. Although individual nurses identified their participation in the program, a group level of participation did not occur. This suggests that a certain level of readiness is required, as hypothesized by Nolan and Grant (1993).

**Implications for Research**

This study adds to the current knowledge on delirium prevention using multicomponent intervention programs by incorporating the perspectives of patients, family caregivers, and staff nurses. This exploratory work suggests there are similar themes regarding the barriers and facilitators of delirium prevention among patients, family caregivers, and staff nurses in an acute care setting. The patients, family caregivers, and staff nurses in this study agreed that medical care, though important, is only one factor contributing to a high quality inpatient experience. Other expectations include honesty and clear communication between the patient, family, and health care team, and opportunities for participation in the plan of care. The subjects in this study made it clear that a therapeutic relationship is what brings patients, families, and nurses together in partnership. They also agreed that they need more unhurried time to make it work. Therefore, further research is needed to explore best practices for supporting an acute care environment that facilitates partnership between patients, families, and nurses. The principal investigator will use these findings on the facilitators and barriers to participation to help guide changes in our acute care system. The goals will be to improve communication between the patient, family, and nurse to maximize outcomes of
hospitalization for the older adult and to help establish an acute care culture that values family-centered care.

This study was undertaken as a research study and not implemented as a unit-based protocol; therefore, participation by staff nurses was voluntary. The nurses who did participate did so through attending the delirium in-service and receiving education on the components of the FPDPP. Overall, for those nurses who participated, the major role was to answer family caregivers’ questions related to the older adult’s medical status as a prerequisite for participating in the FPDPP protocols. Because there was no direct care requirement for nurses in this study, some nurses chose not to learn the protocols of the FPDPP, did not attend the delirium in-service, and did not participate in the study. There were those nurses, who when approached with the FPDPP and concept of family-centered care simply were not interested, did not view delirium in the older hospitalized adult as a serious complication, and did not view the family as a recipient of care which made supporting family caregiver participation a challenge. Future research needs to examine the feasibility of implementing this program as a unit-base protocol with more unit staff involved. Based on the findings of this study, it appears that if staff nurses are integrally and actively involved in the FPDPP in partnership with family caregivers, the success of implementing the FPDPP to prevent delirium in the older hospitalized adult will be feasible.

In this study, an interesting finding was that overall, this sample had improved functioning in a number of domains following participation in the FPDPP. Table 15 compares the presence of the targeted risk factors for delirium at baseline with those present at discharge in the older adult study sample.
Table 15: Risk Factors for Delirium: Baseline Versus Discharge

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Baseline</th>
<th>Discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Impairment, (%)</td>
<td>100</td>
<td>80</td>
</tr>
<tr>
<td>MMSE, mean</td>
<td>21.4</td>
<td>23.9</td>
</tr>
<tr>
<td>ADL Impairment, (%)</td>
<td>93.3</td>
<td>80</td>
</tr>
<tr>
<td>Katz ADL Score, mean</td>
<td>7.7</td>
<td>10.1</td>
</tr>
<tr>
<td>Vision Impairment, (%)</td>
<td>60</td>
<td>60.2</td>
</tr>
<tr>
<td>Hearing Impairment, (%)</td>
<td>60</td>
<td>51</td>
</tr>
<tr>
<td>Whisper Score, mean</td>
<td>6.6</td>
<td>7.8</td>
</tr>
</tbody>
</table>

While all of the older adult subjects had a risk factor of cognitive impairment at baseline screening, only 80% were cognitively impaired at discharge. The mean MMSE score at discharge increased by 2.5 points from baseline (21.4 to 23.9). Ninety-three percent of patients had a risk factor of ADL impairment at baseline, which decreased to 80% at discharge with an increase of 2.4 points in the mean Katz ADL score (7.7 to 10.1) from baseline to discharge. Sixty percent of older adults were hearing impaired at baseline which decreased to 51% at discharge. Only vision impairment remained virtually unchanged, occurring in 60% of participants at baseline and 60.2% at discharge. Of the fifteen study patients, none developed delirium during participation from baseline to discharge in contrast to the findings of a systematic review that identified 42 studies of prevalence and outcomes of delirium in medical inpatients where the occurrence of delirium varied between 11% and 42% (Siddiqi, Horne, House, & Holmes, 2006). It is unclear of the effect of the FPDPP on these variables. Improved functioning following participation in the FPDPP in the cognitive, mobility, vision, and hearing domains may be a consequence of the patients being sicker the first time these tests were administered.
since it was at admission, leading to potentially less ability to attend to and correctly complete test items.

A focus of future study should be examination of the relationship between participation in the FPDPP and both changes in risk factors from baseline to discharge and the occurrence of delirium. Future research will need to include an experimental design study to control for extraneous variables and consideration of effect size, sample size, critical significance level ($\alpha$), and power using statistical hypothesis testing to determine the effect of the FPDPP on these outcomes.

Another finding of note in this study was that at baseline screening the mean Whisper score for older adult patients was 6.6 in the uncovered state (when the researcher’s mouth was not covered when whispering), and 5.3 in the covered state (when the researcher’s mouth was covered). The standard procedure for using the Whisper test to screen for hearing impairment involves testing in the uncovered state. There was a difference in the mean scores between the uncovered and covered states of 1.3 points. Therefore, future research should include the impact of lip-reading on Whisper test scores and thus, screening for hearing impairment.

This study also addressed the challenges of recruiting a sample from a vulnerable population. Of the forty-two recruited older adult patients, twenty-seven patients were excluded because they met one or more of the exclusion criteria. Reasons for exclusion included the presence of delirium ($n=7; 17\%$) and severe hearing impairment ($n=2; <1\%$). For patients without either of these exclusion criteria, other reasons for nonparticipation included refusal by the older adult to give informed consent ($n=9; 34\%$) or refusal by
family caregiver to give informed consent (n=6; 23%). Future research is needed to focus on strategies for effective recruitment of vulnerable populations.

Implications for Practice

Staff nurses addressed the steps of the intervention protocol perceived to have the potential to change the nurse’s practice the most. Each of the targeted intervention protocols is significant to the successful prevention of delirium in the older hospitalized adult (Inouye et al., 1999; Inouye, 2006). However, when asked what step or steps of the intervention protocols were most influential in changing their practice in caring for older hospitalized adults, the staff nurses in this study consistently identified the orientation and therapeutic activities protocols, which targeted cognitive impairment, as having the most potential to impact their daily care activities. The nurses noted how the interventions in the orientation and therapeutic activities protocols, such as orienting communication and environmental strategies, used to promote cognitive status were not consistently performed prior to implementing the FPDPP.

The other intervention protocol that nurses identified as influential in changing their practice was the hearing protocol which targeted hearing impairment. The hearing protocol included education on use of the “Clear Speech Method” and the importance of ensuring that the patient’s hearing aids were operable. Prior to implementing the FPDPP, the nurses noted that little consideration was given to the impact of hearing impairment on communication and the basic communication strategies that they could use to improve the quality of their communication with older adults,

The process of cognitive and sensory interventions by the nurse and the actual critical appraisal of the older adult’s risk factor profile for delirium were not usual care.
Current practice allows for assumptions to be made regarding cognitive and sensory status of older adults which are associated with the older adult’s acutely ill state and as a consequence of perspectives that many nurses hold about aging. The intervention protocols of the FPDPP offer a process by which to place these assumptions in the background and consider the unique cognitive and sensory aspects of the older adult patient, along with the medical condition, in individualizing a comprehensive approach to delirium prevention.

We know the reality is that the acute care environment is overwhelming, not only to work in for nurses, but also for the patients and their families who receive care. In the current health care environment, care of family caregivers can easily be lost unless staff become skilled in providing family-centered care (Chesla, 2006), and until interventions are institutionalized and supported by mechanisms designed to support positive outcomes. Changing a culture requires a process that motivates the leaders with the need to change and sustain efforts over a long period. Despite the need for more research-based knowledge to guide targeted assessments and interventions aimed at including families of patients, nurses can become sensitive to the needs of families and use existing research-based findings to strengthen family-centered care in practice. Collaborative care planning leads to meeting the goals of promoting, supporting, and facilitating active family participation in health care and self determination (Bradley, 2006).

Staff nurses need to feel empowered to take a more proactive approach to changing practice. To support nurses in delivering family-centered care, we need to give them the resources and education to engage in this practice. Resources include adequate staffing so that each nurse has time to answer patient and family questions and written
materials for families to facilitate their participation in the plan of care. Nurses also need to be educated on the components of family-centered care and its implementation, with a focus on the importance of ongoing, consistent communication to family caregivers.
CHAPTER 7

CONCLUSION

The purpose of this study was to examine the feasibility of implementing a family participation delirium prevention program in an acute care setting. The challenge is to develop a delirium prevention program that effectively supports and informs family caregivers of older adults at risk for delirium, working in partnership with the nurses caring for them. From this study, recommendations can be made as to how this partnership can be improved which include: 1) Workshops for staff nurses on various aspects of delirium, to include risk factors, clinical presentation, and prevention strategies, with an emphasis on the need to work in partnership with family caregivers; 2) A letter introducing the geriatric specialist nurse on the unit to be given to family caregivers of older adults on admission, giving the family caregiver the opportunity to discuss any concerns; and, 3) Posters on all the units to support the introductory letter. These strategies can help to facilitate a partnership between the older adult, family caregiver, and staff nurse with the goal of supporting a culture of family-centered care.

According to Peplau (1991), a therapeutic relationship can be defined as “a relationship that develops in predictable ways, with behavior changes from stage to stage” (p.321). In addition to growth and self maintenance, the goals to attaining an effective therapeutic relationship have been identified as the forming and maintaining of a supportive relationship that enables patients and families to express concerns and feel that they have been understood (Williams & Tappan, 1999). In turn, such a relationship maintains and preserves quality of life thereby reducing stress and frustration and the feeling of being isolated.
Participation is a dynamic process that is integral to the work of both nurses and family caregivers. Participation is a difficult concept to define and is often connected with themes such as ‘involvement’, ‘collaboration’, and ‘partnership’ (Cahill, 1998; Jewell, 1994). These themes reflect the difficulty of promoting participation when caring for patients who are acutely ill within the constraints of time, limited teamwork, and the staff unit environment (Myers & MacDonald, 2006). In this study, participation was not seen as a hierarchy of decision-making (Cahill, 1996), but as a process that occurred in the context of caregiving. Partnership was not at the top of the hierarchy, but was an essential process that underpinned participation by identifying the values and beliefs upon which negotiation was based. By virtue of their role, nurses may be in the position of making decisions around care for patients and families. This can lead to a situation of ‘power over’ patients and families (Hawks, 1991). However, in this study these decisions became participatory through the context of the themes of partnership, therapeutic relationships, and environment.

This study highlights the need for staff nurses to develop a therapeutic relationship with the family caregiver as well as the older adult patient to promote participation in a delirium prevention program for the older hospitalized adult. Families who have loved ones undergoing acute episodes of medical and nursing care have needs that are both highly individual and universal. Each patient must be viewed as part of some type of larger whole – a family unit- and the needs of the family must be systematically assessed and addressed by nurses. To the extent that family caregivers are sensitively and effectively integrated into patient care and discharge planning, they may be strengthened in their capacity to optimize patient care and outcomes.
As stated by Hegyvary (1993), the world of practice is comprised of a complex system, which includes multiple factors, multiple effects, and multiple causations. The interplay between the intervention program, the patients receiving care, the family caregivers and staff nurses providing care, and the setting in which the care is provided are interacting to affect the outcomes expected. The factors contributing to family participation in the delirium prevention program highlighted in this study are indeed multiple.

Operating from a framework of family-centered care places the patient and family at the forefront of acute care practice while maximizing patient outcomes. To the extent that families are sensitively and effectively integrated into patient care, they may be strengthened in their capacity to sustain vital functions and optimize patient outcomes. With family-centered care, nurses can emphasize the importance of providing accurate and consistent information to family caregivers, acknowledge the vital role family caregivers play in the recovery and preventive efforts for patients, and advocate for environments that support family caregivers’ participation.

How can we facilitate the use of a family participation program in the real world of clinical practice? Nurses who recognize the research process and the need for continual improvement in patient care, which involves changing practice when indicated, are needed within every practice setting. Nurses who possess the education and competency in delirium prevention interventions and operate from a framework of family-centered care are also necessary. The regulatory atmosphere, workload structure, and patient-family-nurse collaboration are additional elements having an impact on the implementation of a delirium prevention program. This study does not point to one
strategy but does demonstrate that the use of multiple strategies concurrently may be necessary to facilitate the implementation of a delirium prevention program with the potential to improve outcomes for the older hospitalized adult. In the end, if the nurse is not actively involved in partnership with the family caregiver, the implementation of a family participation program for delirium prevention presents more of a challenge. The power of the future success of the FPDPP lies in a multicomponent approach that places emphasis on the active engagement of the family caregiver in partnership with the actively involved nurse.
CHAPTER 8

RESOURCE SHARING PLAN

At the completion of the study, the principal investigator produced results that can be shared as preliminary findings for the availability of participants and the feasibility of family participation in a delirium prevention intervention program. Targeted communication vehicles will be utilized to disseminate the findings to help educate health care providers about evidence based practices for delirium prevention in the older hospitalized adult that partner the nurse and family caregiver. The results will be of interest to specific and distinct audiences including geriatric health care providers; care coordinators and social workers; the nursing research community; leaders in nursing practice; Massachusetts General Hospital leadership; and the students and faculty at UMASS Amherst and the MGH Institute of Health Professions. Upon completion of the study, the principal investigator, Deborah Rosenbloom-Brunton completed a written report on the project and its findings, with input from the dissertation committee, which is suitable for dissemination. Identified target areas for the process of dissemination will occur as follows:

- To disseminate results to geriatric health care providers, care coordinators, and social workers, the principal investigator will prepare articles for submission to the following peer-reviewed journals:
  a. Geriatric health care providers-publication submission to the Journal of Gerontological Nursing and the Journal of the American Geriatric Society
  b. Care coordinators/social workers-publication submission to the Journal of Family Nursing
2. To disseminate results to local and regional nursing leadership and nursing research communities, the principal investigator will present the results at the annual Eastern Nursing Research Society meeting. In addition to sending a final report to the Sigma Theta Tau International honor society, the study abstract data will be registered online in the Virginia Henderson International Nursing Library located at www.nursinglibrary.org The Registry of Nursing Research is a searchable and free resource containing more than 28,000 studies.

3. To share findings with MGH nursing leadership, the principal investigator will present results at:
   a. MGH Annual Nursing Research Week
   b. MGH Nursing Research Committee meetings
   c. MGH Nursing Practice Committee meetings
   d. Publication submission to MGH nursing practice journal, *Caring Headlines*

4. To disseminate results to the students and faculty at UMASS Amherst and at the MGH-IHP, the principal investigator will present the study findings at appropriate forums in the schools of nursing and larger campus communities. These findings about an important partnership among health care providers, patients, and families will stimulate discussions and new teaching/learning opportunities for strategies to avert the negative consequences of hospitalization for older adults. The findings will be posted on the websites of both schools of nursing.
CHAPTER 9

STUDY BUDGET AND TIMETABLE

The dissertation study had a budget that was funded from two grant mechanisms:

(1) The Sigma Theta Tau International Small Research Grant in the amount of $3,224 with a grant funding period that began on June 1, 2008 and ends on May 31, 2009; and,

(2) MGH Institute of Health Professions Faculty Fellowship Award for Geriatric Research in the amount of $10,000 that began on July 1, 2008 and ends on June 30, 2009.

The total budget amount was $12,844. For the two grants, the approved budgets with justification are included in Appendix R.

The timeline for the completed study is included in Appendix S. Four months were allotted for data collection and the remaining time was devoted to data management, analysis, and dissemination.
APPENDICES
APPENDIX A
THEORETICAL SUBSTRUKTION

Interaction

Patient

Risk Factors For Delirium
Cog Immobility Impairment
MMSE
Katz Index

Demographic Factors
Age Gender Admit Dx
Race Ethnicity

Perceived Supportive Nursing Behaviors

Nurse

Demographic Factors
Age Gender Admit Dx
Race Ethnicity

Family Caregiver

Targeted Intervention Protocols
Orientation Protocol
Therapeutic Activities Protocol
Early Mobilization Protocol

Outcomes

Family Participation
Hearing Protocols
Occurrence of delirium

Outcomes

Race Ethnicity

Cognitive Impairment
Vision Hearing Test

Cognitive Impairment
Vision Hearing Test

Cognitive Impairment
Vision Hearing Test

Cognitive Impairment
Vision Hearing Test

Cognitive Impairment
Vision Hearing Test
APPENDIX B

RESOURCES AND FACILITIES

Resources

The following resources were available and were used to complete the study. Resources included those available at the University of Massachusetts Amherst, the academic partner in this study, and those at Massachusetts General Hospital, the practice partner in this study.

University of Massachusetts Amherst. The University of Massachusetts Amherst is a coeducational public institution with a “Doctoral/Research Universities-Extensive” classification and national ranking that confirm its reputation for excellence. The School of Nursing (SON) is accredited by the Commission on Collegiate Nursing Education (CCNE). The SON offers bachelor, masters, postmasters, and doctoral degrees to students through a number of programs, including PhD in Nursing and Doctor of Nursing Practice degrees. Within the SON, there are approximately 80 faculty, including tenured, tenure-track, and clinical faculty. There is access to computer systems, statistical programs, on-line library catalog systems, training sessions, and research consultation. The School of Nursing/School of Public Health and Health Sciences Research Affairs Office actively supports students with grant preparation, data management, and statistical data analysis. This includes assembling the proposal, biosketches, budget development, equipment quotes, and free statistical consultation.

The Biostatistics Consulting Center operates within the Biostatistics and Epidemiology Program in the School of Public Health and has access to a broad range of expertise in modern statistical practices to address all areas of research. The center provides data collection and data entry services and additional support for manuscript and report writing, including statistical analysis, interpretation of results, and collaboration on the writing. The University Library System provides support for graduate studies and research through all collections in the 28 story W. E. B. DuBois Library, including comprehensive materials in the health sciences, social sciences and humanities. The Five College online catalog provides electronic access to library catalog records at the University of the Four Colleges (Amherst, Hampshire, Mount Holyoke, and Smith colleges). The online catalog is the current record of collections and provides a variety of ways in which to access library holdings information.

Facilities

Massachusetts General Hospital. Data collection occurred at Massachusetts General Hospital (MGH), a 903 bed academic medical center in Boston, MA. MGH serves as a national resource for specialty medical care and research while providing comprehensive medical services to the local community. MGH serves as the primary campus for Harvard Medical School. With over 4,000 nurses employed, the hospital has been designated twice as a Magnet™ hospital for excellence in nursing services by the
American Nurses Credentialing Center (ANCC). The MGH Treadwell Library has an extensive paper and online collection of health services research journals and clinical references. The Blum Patient and Family Learning Center is a consumer health library that is available to patients and families to assist with informed choices.

The Massachusetts General Hospital Institute of Health Professions. The Massachusetts General Hospital Institute of Health Professions (MGH-IHP) actively supports faculty in development of a research career including grant fellowship awards. The MGH-IHP has awarded the principal investigator a grant of $10,000 as a Geriatric Fellow to support this geriatric nursing research study. As a full time member of the nursing faculty, the principal investigator has an office with a computer and printer. A locked file cabinet in the principal investigator’s office will be the storage location for the coded data. The MGH-IHP has internet access that is directly linked to MGH and a professional informatics team to deal with computer related problems. Faculty members have access to the Mallinckrodt General Clinical Research Center at MGH, which is an NIH funded Center to support investigator initiated research programs. MGH-IHP faculty can consult with the biostatistician at no charge.
APPENDIX C

CONSULTATIVE SUPPORT

The research team is uniquely qualified to address the feasibility of a family protocol for delirium prevention in the older hospitalized adult. The team included nurses, scientists, communication experts, and physicians who have specific experience and expertise to contribute to the study.

Deborah Rosenbloom-Brunton (Principal investigator). Deborah Rosenbloom-Brunton, a graduate student in the PhD in Nursing Program at University of Massachusetts Amherst (UMASS Amherst) conducted this study to fulfill her dissertation research requirement and contribute to the development of an intervention for delirium prevention with increased potential for use by family caregivers in the acute care setting. Ms. Rosenbloom-Brunton has a full-time appointment as the Coordinator of the Acute Care Specialty, Graduate Program in Nursing, at the Massachusetts General Hospital Institute of Health Professions (MGH-IHP) and practices as an Acute Care Nurse Practitioner at Brigham and Women’s Hospital in Boston, MA. She received her Master of Science in Nursing degree from the MGH-IHP and has 10 years of clinical practice experience in acute care nursing. As an educator, she has collaborated with staff nurses as a clinical faculty member for student nurses on medical-surgical and critical care units in acute care hospitals. Ms. Rosenbloom-Brunton’s clinical practice focuses on an inpatient, primarily geriatric, population. Her research focus has been on risk factors for delirium in the older hospitalized adult and the use of evidence-based strategies for delirium prevention. Ms. Rosenbloom-Brunton coordinated the study and oversaw the graduate research assistants. She will coordinate and participate in the presentations and publications. She devoted 100% time and effort on the dissertation for the duration of the study.

Elizabeth A. Henneman (Dissertation advisor/mentor). Dr. Henneman is an Assistant Professor of Nursing at UMASS Amherst and a staff nurse in the Medical Surgical Intensive Care Unit at Baystate Medical Center in Springfield, MA. She received her PhD in Nursing at the University of California, Los Angeles. Dr. Henneman has conducted extensive research on patient safety. She is the co-principal investigator on a National Science Foundation Grant evaluating the safety of medication processes. She is an expert in exploratory descriptive methods and has used this design extensively in her research. Dr. Henneman reviewed procedures used to collect and analyze data and supported the principal investigator in the conduct of a rigorous study with the potential to improve outcomes of hospitalization for older adults.

Cynthia Jacelon (Dissertation committee). Dr. Jacelon is an Assistant Professor in the School of Nursing at UMASS Amherst. She received a PhD in Nursing from New York University and completed a postdoctoral fellowship in gerontology at Yale School of Nursing in 2005. Dr. Jacelon is an expert in qualitative research methodology and gerontological nursing. She is a certified rehabilitation registered nurse with extensive
research experience focused on the maintenance of dignity in older adults. Dr. Jacelon provided expertise in qualitative methodology and gerontological nursing research.

**Carol Bigelow (Dissertation committee).** Dr. Bigelow is a Research Assistant Professor in the School of Public Health and Health Sciences at UMASS Amherst. She is a graduate of the University of Washington where she received a PhD in Biostatistics. She has demonstrated expertise in statistics and quantitative research methodology with an extensive and ongoing research career. Dr. Bigelow provided expert consultation for the research design and data analysis procedures.

**Karen Helfer. (Dissertation committee).** Dr. Helfer is an Associate Professor and the Graduate Program Director of the Department of Communication Disorders at UMASS Amherst. She received her PhD in Audiology from Northwestern University, Chicago, IL and has conducted extensive research on speech understanding, the effects of aging on auditory and visual sensation, and effective communication strategies for older adults. She provided consultation around refinement of the orientation, hearing, and vision protocols of the Family Participation Delirium Prevention Program in order to maximize cognitive and communication support strategies for the older adult.

**Sharon Inouye. (Consultant).** Dr Inouye is the director of the Aging Brain Center at Hebrew Senior Life in Boston, MA and Professor of Medicine at Harvard Medical School and Beth Israel Medical Center. Dr Inouye has conducted groundbreaking research work on delirium, resulting in over 75 published articles to date, beginning with the development and validation of the Confusion Assessment Method in 1990 for the identification of delirium, which is currently the most widely used standardized tool for delirium screening for older hospitalized adults. Dr. Inouye helped to conceptualize the multifactorial model for the etiology of delirium, which identified the predisposing and precipitating risk factors for older hospitalized adults. As a co-investigator in the Delirium Prevention Trial, she helped to develop and test a multicomponent intervention strategy to prevent delirium targeted toward the six major predisposing and precipitating risk factors for delirium. The multicomponent intervention strategy was found to decrease the incidence of delirium by 40%. From the findings of the Delirium Prevention Trial, Dr Inouye led the development of The Hospital Elder Life Program (HELP). The HELP program has undergone national dissemination as an inpatient intervention strategy to prevent delirium in the older hospitalized adult using trained Elder Life Specialists. Dr. Inouye has graciously supported the modification of the HELP program for implementation by family caregivers of older adults. She has consulted on the modification of the original HELP protocols for family implementation, the development of strategies for effective implementation of the Family Participation Delirium Prevention Program, and the design for teaching manuals and videos for family caregivers.

**Graduate research assistants.** Two graduate nursing students acted as research assistants for data collection and analysis. The research assistants are advanced practice nursing students in the acute care nurse practitioner track at MGH Institute of Health Professions who volunteered to participate as an alternative to their degree requirement of a master’s thesis. This experience provided the advanced-practice nursing students with
the opportunity to participate in the research process through data collection, analysis, and dissemination activities. After careful training by the principal investigator, the research assistants assisted in the training of family caregivers in the intervention protocols and the procedures for tracking of intervention completion. Research assistants also assumed an important role in the content analysis of questionnaire responses. Each of the research assistants worked on the project 50% for 1 full time employee. They were compensated with conferring of 3 credits for the master’s thesis degree requirement.
APPENDIX D

OLDER ADULT INFORMED CONSENT FORM
About this consent form

Please read this form carefully. It tells you important information about a research study. A member of our research team will also talk to you about taking part in this research study. People who agree to take part in research studies are called “subjects.” This term will be used throughout this consent form. If you have any questions about the research or about this form, please ask us. If you decide to take part in this research study, you must sign this form to show that you want to take part. We will give you a copy of this form to keep.

Why is this research study being done?

The purpose of this research study is to examine a program design to prevent delirium (confusion) in people who are in the hospital. Older adults who are hospitalized may be prone to confusion. We are evaluating a program to decrease the risk of confusion. We hope to use what we learn from this research study to support family members in helping their loved ones prevent confusion during hospitalization. About 10 family members of older adult inpatient subjects will take part in this research study. We expect to enroll about 10 older adult inpatient subjects from White 11 and Bigelow 11 at Massachusetts General Hospital (MGH).
How long will I take part in this research study?

This study will last long as you are in the hospital. During this time your family will be asked to make daily visits with you, which typically last about one-half hour to two hours. Once the research study is completed, you will receive a phone call to share with you the findings.

What will happen in this research study?

Description of Study Visits:
The procedures will include:

- Taking part in the recommended activities daily with your family member
- Brief daily meeting with the researcher to test for any changes in your cognitive status and answer questions

What are the risks and possible discomforts from being in this research study?

There is a risk that when walking with your family member you might fall. Your family member will be asking your nurse if this is safe to avoid this problem.

There is a risk that you may become tired during participation in the activities with your family member as you are in the hospital for an illness. If you become tired during the activities, let your family member know that you wish to rest.

The other risks to you are no greater than those of normal care activities as the things you will be doing are similar to things you might do when you are home.

There may be other risks that are not known at this time.

The principal researcher or your nurse will be available to discuss any concerns you might have.

What are the possible benefits from being in this research study?
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 Participation in the assigned activities may decrease your risk of becoming confused while you are in the hospital. You and your family member may not benefit from this research study. Other older adults at risk for confusion may benefit in the future from what we learn in this research study.

What other treatments or procedures are available for my condition?

You will receive standard medical and nursing treatments as prescribed by your medical team to prevent delirium. These will include the medical and nursing therapies directed toward reason that you were admitted.

Can I still get medical care within Partners if I don’t take part in this research study, or if I stop taking part?

Yes. Your decision won’t change the medical care you get within Partners now or in the future. There will be no penalty, and you won’t lose any benefits you receive now or have a right to receive.

Taking part in this research study is up to you. You can decide not to take part. If you decide to take part now, you can change your mind and drop out later. We will tell you if we learn new information that could make you change your mind about taking part in this research study.

If you take part in this research study, and want to drop out, you should tell us. We will make sure that you stop the study safely. We will also talk to you about follow-up care, if needed.

It is possible that we will have to ask you to drop out before you finish the study. If this happens, we will tell you why. We will also help arrange other care for you, if needed.

Your decision also won’t change the medical care your family member gets within Partners now or in the future.
Will I be paid to take part in this research study?

Your family member will receive a parking voucher at the end of each study visit. Your family member will also receive $5.00 for each completed visit toward meal expenses.
What will I have to pay for if I take part in this research study?

You will not have additional costs if you take part in this research.

What happens if I am injured as a result of taking part in this research study?

We will offer you the care needed to treat any injury that directly results from taking part in this research study. We reserve the right to bill your insurance company or other third parties, if appropriate, for the care you get for the injury. We will try to have these costs paid for, but you may be responsible for some of them.

Giving you care does not mean that Partners hospitals or researchers are at fault, or that there was any wrongdoing. There are no plans for Partners to pay you or give you other compensation for the injury. However, you are not giving up any of your legal rights by signing this form.

If you think you have been injured or have experienced a medical problem as a result of taking part in this research study, tell the person in charge of this study as soon as possible. The researcher's name and phone number are listed in the next section of this consent form.

If I have questions or concerns about this research study, whom can I call?

You can call us with your questions or concerns. Our telephone numbers are listed below. Ask questions as often as you want.

Deborah Rosenbloom-Brunton, MSN, APRN-BC, PhD(c) is the person in charge of this research study. You can call her at (508) 662-8972 at any hour. You can also call Beth Henneman, PhD, University of Massachusetts Dissertation Advisor, (413) 545-1302, with questions about this research study.

If you have questions about study visits, call Deborah Rosenbloom-Brunton at (508) 662-8972.
If you want to speak with someone not directly involved in this research study, please contact the Partners Human Research Committee office. You can call them at 617-424-4100.

You can talk to them about:
- Your rights as a research subject
- Your concerns about the research
- A complaint about the research

Also, if you feel pressured to take part in this research study, or to continue with it, they want to know and can help.

**If I take part in this research study, how will you protect my privacy?**

Federal law requires Partners (Partners HealthCare System and its hospitals, health care providers and researchers) to protect the privacy of health information that identifies you. This information is called Protected Health Information. In the rest of this section, we refer to this simply as "health information."

If you decide to take part in this research study, your health information may be used within Partners and may be shared with others outside of Partners, as explained below.

**We have marked with a ☑️ how we plan to use and share your health information. If a box is not checked ☐️, it means that type of use or sharing is not planned for in this research study.**

We will also give you the **Partners Notice for Use and Sharing of Protected Health Information.** The Notice gives more details about how we use and share your health information.

- **Health Information About You That Might be Used or Shared During This Research**
  - ☑️ Information from your hospital or office health records within Partners or elsewhere, that may be reasonably related to the conduct and oversight of the research study. If health information is needed from your doctors or hospitals
outside Partners, you will be asked to give permission for these records to be sent to researchers within Partners.

- New health information from tests, procedures, visits, interviews, or forms filled out as part of this research study

**Why Health Information About You Might be Used or Shared with Others**

The reasons we might use or share your health information are:

- To do the research described above
- To make sure we do the research according to certain standards - standards set by ethics and law, and by quality groups
- For public health and safety - for example, if we learn new health information that could mean harm to you or others, we may need to report this to a public health or a public safety authority
- For treatment, payment, or health care operations

**People and Groups That May Use or Share Your Health Information**

1. **People or groups within Partners**
   - Researchers and the staff involved in this research study
   - The Partners review board that oversees the research
   - Staff within Partners who need the information to do their jobs (such as billing, or for overseeing quality of care or research)

2. **People or groups outside Partners**
   - People or groups that we hire to do certain work for us, such as data storage companies, our insurers, or our lawyers
   - Federal and state agencies (such as the U.S. Department of Health and Human Services, the Food and Drug Administration, the National Institutes of Health, and/or the Office for Human Research Protections) and other U.S. or foreign government bodies, if required by law or involved in overseeing the research
   - Organizations that make sure hospital standards are met
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☐ The sponsor(s) of the research study, and people or groups it hires to help perform this research study
☐ Other researchers and medical centers that are part of this research study
☐ A group that oversees the data (study information) and safety of this research study
☒ Other: Beth Henneman, PhD, PhD dissertation advisor, University of Massachusetts Amherst School of Nursing

Some people or groups who get your health information might not have to follow the same privacy rules that we follow. We share your health information only when we must, and we ask anyone who receives it from us to protect your privacy. However, once your information is shared outside Partners, we cannot promise that it will remain private.

• Time Period During Which Your Health Information Might be Used or Shared With Others
  • Because research is an ongoing process, we cannot give you an exact date when we will either destroy or stop using or sharing your health information.

• Your Privacy Rights
  • You have the right not to sign this form permitting us to use and share your health information for research. If you don’t sign this form, you can’t take part in this research study. This is because we need to use the health information of everyone who takes part in this research study.
  • You have the right to withdraw your permission for us to use or share your health information for this research study. If you want to withdraw your permission, you must notify the person in charge of this research study in writing.

If you withdraw your permission, we will not be able to take back information that has already been used or shared with others. This includes information used or shared to carry out the research study or to be sure the research is safe and of high quality.

If you withdraw your permission, you cannot continue to take part in this research study.

• You have the right to see and get a copy of your health information that is used or shared for treatment or for payment. To ask for this information, please contact the person in charge of this research study.
• **If Research Results Are Published or Used to Teach Others**
  The results of this research study may be published in a medical book or journal, or used to teach others. However, your name or other identifying information **will not** be used for these purposes without your specific permission.

**Consent/Assent to take part in this research study, and authorization to use or share your health information for research**

**Statement of Subject or Person Giving Consent/Assent**

- I have read this consent form.
- This research study has been explained to me, including risks and possible benefits (if any), other options for treatments or procedures, and other important things about the study.
- I have had the opportunity to ask questions.

If you understand the information we have given you, and would like to take part in this research study, and also agree to allow your health information to be used and shared as described above, then please sign below:

**Signature of Subject:**

______________________________
Adults or Minors, ages 14-17

______________________________
Date/Time

**OR**

If you understand the information we have given you, and would like to give your permission for your child/the person you are authorized to represent to take part in this research study, and also
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Protocol Title: Feasibility of Family Participation in A Delirium Prevention Program For The Older Hospitalized Adult

Principal Investigator: Deborah Rosenbloom-Brunton, MS, ACNP-BC

Site Principal Investigator: [Blank]

Description of Subject Population: Family caregivers of older adults at risk for delirium

About this consent form

Please read this form carefully. It tells you important information about a research study. A member of our research team will also talk to you about taking part in this research study. People who agree to take part in research studies are called “subjects.” This term will be used throughout this consent form. If you have any questions about the research or about this form, please ask us. If you decide to take part in this research study, you must sign this form to show that you want to take part. We will give you a copy of this form to keep.

Why is this research study being done?

The purpose of this research study is to examine a program designed to prevent delirium (confusion) in older adult inpatients. We are asking you to take part because your older adult relative may be at risk for confusion during hospitalization. You may be able to help avoid this problem by doing certain things. We hope to use what we learn from this research study to support family members in helping prevent confusion in older adults during hospitalization. About 10 family members of older adults will be enrolled as subjects for this research study. We
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expect to enroll about 10 older adult inpatients from White 11 and Bigelow 11 at Massachusetts General Hospital (MGH).

**How long will I take part in this research study?**

This study will continue as long as your family member is in the hospital. During this time you will be asked to make daily visits, which typically last about **one-half hour to two hours**. Once the research study is completed, you will receive a phone call to share with you the findings.

**What will happen in this research study?**

Description of Study Visits
The procedures will include:
- Training by the principal researcher in five strategies to prevent delirium (confusion). The training will occur during a one hour session before you start the study. You will learn strategies to help prevent delirium (confusion) in your family member. This will include things like reading the newspaper with your family member, walking with him or her, and making sure glasses or hearing aids are on
- Taking part in the recommended activities daily with your family member. This will require daily visits, typically lasting one hour
- Keeping track on a form of how many of these strategies were finished
- Completing a questionnaire at the end of the study. The questionnaire will ask you what things you found to be difficult and what things were easy and should take about 15 minutes. While we hope that you will answer all of the questions you can skip any questions you don’t want to answer.

**What are the risks and possible discomforts from being in this research study?**

Risks: Risks of this study include the time commitment for daily visits, which may require that you rearrange your schedule in order to participate. Your daily visits can be at any time during visiting hours.
There may be other risks that are not known at this time.

The principal researcher or nurse for your family member will be available to discuss any concerns you might have.

**What are the possible benefits from being in this research study?**

You and your family member may not benefit from this research study. However, we hope that you can help us prevent your family member from developing confusion while in the hospital. Other older adults at risk for confusion may benefit in the future from what we learn in this research study.

**What other treatments or procedures are available for my condition?**

Your family member will receive standard medical and nursing treatments as prescribed by your medical team to prevent delirium. These will include the medical and nursing therapies directed toward reason that your family member was admitted.

**Can I still get medical care within Partners if I don’t take part in this research study, or if I stop taking part?**

Yes. Your decision won’t change the medical care you get within Partners now or in the future. There will be no penalty, and you won’t lose any benefits you receive now or have a right to receive.

Taking part in this research study is up to you. You can decide not to take part. If you decide to take part now, you can change your mind and drop out later. We will tell you if we learn new information that could make you change your mind about taking part in this research study.

If you take part in this research study, and want to drop out, you should tell us. We will make sure that you stop the study safely. We will also talk to you about follow-up care, if needed.

It is possible that we will have to ask you to drop out before you finish the study. If this happens, we will tell you why. We will also help arrange other care for you, if needed.
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Your decision also won’t change the medical care your family member gets within Partners now or in the future.

Will I be paid to take part in this research study?

You will receive a parking voucher at the end of each study visit. You will also receive $5.00 for each completed visit toward meal expenses.

What will I have to pay for if I take part in this research study?

You will not have additional costs if you take part in this research.

What happens if I am injured as a result of taking part in this research study?

We will offer you the care needed to treat any injury that directly results from taking part in this research study. We reserve the right to bill your insurance company or other third parties, if appropriate, for the care you get for the injury. We will try to have these costs paid for, but you may be responsible for some of them.

Giving you care does not mean that Partners hospitals or researchers are at fault, or that there was any wrongdoing. There are no plans for Partners to pay you or give you other compensation for the injury. However, you are not giving up any of your legal rights by signing this form.

If you think you have been injured or have experienced a medical problem as a result of taking part in this research study, tell the person in charge of this study as soon as possible. The researcher’s name and phone number are listed in the next section of this consent form.

If I have questions or concerns about this research study, whom can I call?
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You can call us with your questions or concerns. Our telephone numbers are listed below. Ask questions as often as you want.

Deborah Rosenbloom-Brunton, MSN, APRN-BC, PhD(c) is the person in charge of this research study. You can call her at (508) 662-8972 at any hour. You can also call Beth Henneman, PhD, University of Massachusetts Dissertation Advisor, (413) 545-1302, with questions about this research study.

If you have questions about study visits, call Deborah Rosenbloom-Brunton at (508) 662-8972.

If you want to speak with someone not directly involved in this research study, please contact the Partners Human Research Committee office. You can call them at 617-424-4100.

You can talk to them about:
- Your rights as a research subject
- Your concerns about the research
- A complaint about the research

Also, if you feel pressured to take part in this research study, or to continue with it, they want to know and can help.

If I take part in this research study, how will you protect my privacy?

Federal law requires Partners (Partners HealthCare System and its hospitals, health care providers and researchers) to protect the privacy of health information that identifies you. This information is called Protected Health Information. In the rest of this section, we refer to this simply as “health information.”

If you decide to take part in this research study, your health information may be used within Partners and may be shared with others outside of Partners, as explained below.

We have marked with a ☑ how we plan to use and share your health information. If a box is not checked ☐, it means that type of use or sharing is not planned for in this research study.
We will also give you the Partners Notice for Use and Sharing of Protected Health Information. The Notice gives more details about how we use and share your health information.

- **Health Information About You That Might be Used or Shared During This Research**
  - Information from your hospital or office health records within Partners or elsewhere, that may be reasonably related to the conduct and oversight of the research study. If health information is needed from your doctors or hospitals outside Partners, you will be asked to give permission for these records to be sent to researchers within Partners.
  - New health information from tests, procedures, visits, interviews, or forms filled out as part of this research study

- **Why Health Information About You Might be Used or Shared with Others**
The reasons we might use or share your health information are:
  - To do the research described above
  - To make sure we do the research according to certain standards - standards set by ethics and law, and by quality groups
  - For public health and safety - for example, if we learn new health information that could mean harm to you or others, we may need to report this to a public health or a public safety authority
  - For treatment, payment, or health care operations

- **People and Groups That May Use or Share Your Health Information**
  1. **People or groups within Partners**
     - Researchers and the staff involved in this research study
     - The Partners review board that oversees the research
     - Staff within Partners who need the information to do their jobs (such as billing, or for overseeing quality of care or research)
  2. **People or groups outside Partners**
People or groups that we hire to do certain work for us, such as data storage companies, our insurers, or our lawyers

Federal and state agencies (such as the U.S. Department of Health and Human Services, the Food and Drug Administration, the National Institutes of Health, and/or the Office for Human Research Protections) and other U.S. or foreign government bodies, if required by law or involved in overseeing the research

Organizations that make sure hospital standards are met

The sponsor(s) of the research study, and people or groups it hires to help perform this research study

Other researchers and medical centers that are part of this research study

A group that oversees the data (study information) and safety of this research study

Other: Beth Henneman, PhD, PhD dissertation advisor, University of Massachusetts Amherst School of Nursing

Some people or groups who get your health information might not have to follow the same privacy rules that we follow. We share your health information only when we must, and we ask anyone who receives it from us to protect your privacy. However, once your information is shared outside Partners, we cannot promise that it will remain private.

- **Time Period During Which Your Health Information Might be Used or Shared With Others**
  - Because research is an ongoing process, we cannot give you an exact date when we will either destroy or stop using or sharing your health information.

- **Your Privacy Rights**
  - You have the right **not** to sign this form permitting us to use and share your health information for research. If you don’t sign this form, you can’t take part in this research study. This is because we need to use the health information of everyone who takes part in this research study.
  - You have the right to withdraw your permission for us to use or share your health information for this research study. If you want to withdraw your permission, you must notify the person in charge of this research study in writing.
If you withdraw your permission, we will not be able to take back information that has already been used or shared with others. This includes information used or shared to carry out the research study or to be sure the research is safe and of high quality.

If you withdraw your permission, you cannot continue to take part in this research study.

- You have the right to see and get a copy of your health information that is used or shared for treatment or for payment. To ask for this information, please contact the person in charge of this research study.

- **If Research Results Are Published or Used to Teach Others**

  The results of this research study may be published in a medical book or journal, or used to teach others. However, your name or other identifying information **will not** be used for these purposes without your specific permission.

**Consent/Assent to take part in this research study, and authorization to use or share your health information for research**

**Statement of Subject or Person Giving Consent/Assent**

- I have read this consent form.
- This research study has been explained to me, including risks and possible benefits (if any), other options for treatments or procedures, and other important things about the study.
- I have had the opportunity to ask questions.

If you understand the information we have given you, and would like to take part in this research study, and also agree to allow your health information to be used and shared as described above, then please sign below:

**Signature of Subject:**
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Adults or Minors, ages 14-17

Date/Time

OR

If you understand the information we have given you, and would like to give your permission for your child/the person you are authorized to represent to take part in this research study, and also agree to allow his/her health information to be used and shared as described above, then please sign below:

Signature of Parent(s)/Guardian or Authorized Representative:

Parent(s)/Guardian of Minor

Date/Time

OR

Court-appointed Guardian or Health Care Proxy

Date/Time

OR

Family Member/Next-of-Kin

Date/Time

Relationship to Subject:

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Signature of a Witness:

Witness (when required by the PHRC or sponsor) ____________________________ Date/Time ____________________________

Statement of Study Doctor or Person Obtaining Consent

- I have explained the research to the study subject, and
- I have answered all questions about this research study to the best of my ability.

Study Doctor or Person Obtaining Consent ____________________________ Date/Time ____________________________

In certain situations, the Partners Human Research Committee (PHRC) will require that a subject advocate also be involved in the consent process. The subject advocate is a person who looks out for the interests of the study subject. This person is not directly involved in carrying out the research. By signing below, the subject advocate represents (or “says”) that the subject has given meaningful consent to take part in the research study.

Statement of Subject Advocate Witnessing the Consent Process

- I represent that the subject or authorized individual signing above has given meaningful consent.

Subject Advocate (when required by the PHRC or sponsor) ____________________________ Date/Time ____________________________

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APPENDIX F

RECRUITMENT LETTER FOR OLDER ADULT SUBJECTS

Dear White 11 and Bigelow 11 Inpatients,

I am writing to tell you about a research study being conducted at Massachusetts General Hospital by Deborah Rosenbloom-Brunton, PhD(c), RN, ACNP-BC. I am letting older adult patients who are at risk for confusion while in the hospital know about this research project, in case they would like to participate.

Ms. Rosenbloom-Brunton is doing a study that will involve your family member who often has a desire to participate in your hospital care. The study will examine a program delivered to you by your family member that is designed to prevent the complication of confusion while in the hospital. Ms. Rosenbloom-Brunton hopes to use what is learned from this study to support family members in preventing complications that can occur during hospitalization for older adults.

The investigators are looking for hospitalized patients age 65 years and older, who are at risk for confusion. Participation would involve your family member being trained in 5 strategies developed to prevent confusion, things like reading the newspaper with you, walking with you, and making sure your glasses or hearing aids are available. Your family member will receive $50.00 for parking and his or her time, upon completion of participation in the study.

You will not receive any personal health benefits as a result of your participation in this research study. We hope that the results will help us understand confusion better, and in the future, help to prevent confusion in older hospitalized adults.

Your participation is voluntary. Whether you participate or not will have no effect on the medical care you receive here at Massachusetts General Hospital.

Thank you in advance for considering this request,

Sincerely,

House Physician, MD
White 11, Bigelow 11
(XXX) XXX-XXXX

Deborah Rosenbloom-Brunton, PhD(c), RN, ACNP-BC
University of Massachusetts Amherst; MGH Institute of Health Professions
(508) 662-8972
### APPENDIX G

**ESC QUESTIONNAIRE AND ACCEPTABLE ANSWERS FOR RESEARCH STUDY**

<table>
<thead>
<tr>
<th>Question</th>
<th>Acceptable Answer(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What are two potential risks?</td>
<td>Falls, fatigue, no risk</td>
</tr>
<tr>
<td>2. What is expected from you, the patient?</td>
<td>Taking part in recommended activities with family members; answer questions; have cognitive status evaluated</td>
</tr>
<tr>
<td>3. What if you don’t want to continue?</td>
<td>Ask to stop</td>
</tr>
<tr>
<td>4. What if you experience discomfort?</td>
<td>Say something, ask to stop</td>
</tr>
<tr>
<td>5. Why is this study being done?</td>
<td>To examine a program to prevent delirium/confusion in people who are in the hospital</td>
</tr>
</tbody>
</table>
APPENDIX H

FAMILY CAREGIVER DEMOGRAPHIC DATA QUESTIONNAIRE

Study ID #: C___

Age:

Gender: Male ☐ Female ☐

Race
American Indian or Alaskan native ☐
Asian or Pacific Islander ☐
Black ☐
Hispanic ☐
White ☐
Other____________________

Ethnicity
Not of Hispanic origin ☐
Hispanic origin ☐

Education
Less than high school ☐
High school or GED ☐
Some college ☐
College graduate or more ☐

Relationship to patient:
Spouse ☐
Significant other ☐
Adult child ☐
Other blood relative ☐
Other _____________________
APPENDIX I
COPYRIGHT PERMISSION
Hospital Elder Life Program
Non-Exclusive License Agreement

THIS HOSPITAL ELDER LIFE PROGRAM NON-EXCLUSIVE LICENSE AGREEMENT is entered into as of this ___ day of ___, 2006 (the “Effective Date”), by and between INSTITUTE FOR AGING RESEARCH, HEBREW SENIORLIFE, (“IFAR”), a Massachusetts not-for-profit corporation located in Boston, Massachusetts, and Ms. Deborah Rosenbloom-Branton, MSN, APRN-BC, (“Licensee”).

WHEREAS, Sharon Inouye, M.D., M.P.H., a faculty member of IFAR has developed a copyrighted program of videotapes, printed materials, software, and protocols designed to assist in preventing delirium and functional decline among hospitalized elder adults (the “Hospital Elder Life Program” or the “Program”); and Licensee is interested in using the family protocols from the program in a research project involving elderly adults.

NOW, THEREFORE, in consideration of the mutual promises and obligations stated in this Agreement, the parties hereto agree as follows:

1. Term. This Agreement shall be effective as of the date first written above until terminated by either of the parties, with or without cause, upon written notice given to the other at least fourteen (14) calendar days prior to the noticed termination date.

2. Non-Exclusive, Limited License. Upon IFAR’s receipt of an executed copy of this Agreement from Licensee, IFAR shall deliver to Licensee materials that comprise the family protocols from the Program, which represent copyrighted materials. Concurrent with its delivery of the Materials to Licensee, IFAR grants Licensee a limited, revocable, non-exclusive license to use the Materials for the research project, without right to copy any Materials for external use or external distribution outside the hospital. Licensee agrees not to distribute the Materials to any third party without prior written permission by IFAR. Licensee shall devote its best effort, consistent with the practices and procedures under which it protects its own similar materials, to protect the Program and Materials against any unlawful use or copying. Licensee shall return the Materials to IFAR upon any termination of this Agreement, without retaining any copies.

3. Copyright, Attribution. Except for such limited right of use, Licensee shall not assert any right, title, or interest in or to the Program or any related documentation. Licensee acknowledges the validity of the copyright held in the Materials by Dr. Inouye, and agrees that any copies of Materials made by Licensee pursuant to this Agreement shall bear the legend: “© 1999 Sharon K. Inouye, M.D., M.P.H.” All derivative products developed by the Licensee shall also bear this copyright. IFAR claims and reserves to itself and Dr. Inouye all rights and benefits afforded under U.S. copyright law and all international copyright conventions in the Program and Materials. Licensee agrees to make the following attribution to the Hospital Elder Life Program and Dr. Sharon Inouye in any publication or presentation of the results arising from its use of the Program or Materials, including but not limited to all abstracts, posters, presentations, manuscripts, articles, and grant applications: “Based on the Hospital Elder Life Program, ©1999 Sharon K. Inouye, M.D., M.P.H.” Licensee agrees to provide Dr. Inouye with a copy of any publications which contain results obtained from the use of the Materials.

4. Agreement. Licensee shall return the agreement to:
   Dianne C. Huckaby, MBA
   Vice President Research Administration
5. **Limitation of Remedies; Indemnity.** Licensee agrees that the Program does not address many situations that may arise in dealing with the hospitalized elderly, and that persons using Program Materials must continue to exercise their independent judgment about such clinical situations. Licensee’s use of the Program and Materials is at its sole risk. IFAR AND DR. INOUYE DISCLAIM ANY AND ALL PROMISES, REPRESENTATIONS, AND WARRANTIES, EXPRESS OR IMPLIED, EXCEPT AS EXPRESSLY SET FORTH IN THIS AGREEMENT, WITH RESPECT TO THE PROGRAM, THE MATERIAL AND ANY PORTION OF EITHER, INCLUDING WITH RESPECT TO THEIR CONDITION, CONFORMITY TO ANY REPRESENTATION OR DESCRIPTION, TITLE, AND MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE OR USE. In no event shall IFAR or Dr. Inouye be liable to Licensee for any loss of revenue, any incidental, special, exemplary, or consequential damages, or any claims or demands brought against Licensee related to the Program or Licensee’s use of the Program, even if one or both has been advised of the possibility of such damages. Licensee agrees to indemnify IFAR and hold IFAR harmless from and against any and all losses, claims, damages, suits, actions or liabilities of any kind resulting from Licensee’s use of or reliance on the Program.

6. **Miscellaneous.** Neither party may assign or transfer its rights or obligations under this Agreement without the prior written consent of the other party. This Agreement shall be governed and construed in all respects in accordance with the laws of the State of Massachusetts, without regard to its conflicts of laws provisions, to the extent permitted under applicable federal law and regulations. This Agreement may be modified only in writing signed by the party against whom enforcement thereof is sought. Notices shall be in writing and delivered by overnight mail service with a nationwide tracking capability or by facsimile with receipt confirmation to the following persons at the following addresses: (For IFAR): Dianne C. Huckaby, MBA, Vice President Research Administration, Institute for Aging Research, 1200 Centre Street, Boston, Massachusetts 02131

(For Licensee):

IN WITNESS WHEREOF, the parties have caused this Agreement to be executed by their duly authorized representatives as of the date first written above

**HOSPITAL ELDER LIFE PROGRAM**

**LICENSEE:**

By: [Signature]  

Print Name: Dianne C. Huckaby  

Its: Vice President, Research Administration

**IFAR/HSL**

By: [Signature]  

Print Name: [Surname]  

Its: [Position]
FAMILY PARTICIPATION DELIRIUM PREVENTION PROGRAM
PROTOCOLS

Developed by Deborah Rosenbloom-Brunton, PhD(c), ACNP-BC, from Hospital Elder Life Program Protocols (HELP program, Copyright 2000)

ORIENTATION

Older persons who show no signs of confusion at home may become quite confused or forgetful in the hospital or in a new or unfamiliar environment. In fact, this is quite common. Illness, an unfamiliar environment, new medications all can take a toll on the body and mind.

Purpose: To prevent confusion from developing

Techniques:

- **Orienting Communication**
  Orientation refers to a person’s knowledge about where they are, what the date is, who their family members are, etc. This technique is designed to provide the person with the information they need to stay mentally aware of reality. Communication of this information should be provided both verbally and in writing.
  - When talking to the person, include useful and specific reminder of time and place in conversation. For example, the day of the week, month, date, year and location within the hospital
  - Update your loved one daily with information about his or her plan of care including
    - Names of doctors, nurse and nursing assistant for the shift
    - Meal times
    - Tests and procedures schedules with times if known
  - It is important that the person is able to both hear and see the information being given
    - Make sure glasses and hearing aids are in place if worn, and that they are clean and working correctly
    - Turn off the TV and radio if talking with the person, and face them so that they may see your lips

- **Orienting Environment**
  It is critical that the person’s eyeglasses, hearing aids, and dentures be available at all times. It may be helpful to create a comfortable environment by:
  - Posting cards and drawings
  - Making sure a clock with the correct times is visible
  - Arranging flowers, gifts, and plants in sight
• Bringing in objects from home such as religious objects, family photos, favorite clothing, or blanket/afghan

**THERAPEUTIC ACTIVITIES**

Recreational or leisure activity provides balance during the recovery period.

**Purpose:** These activities are meant to boost self esteem, encourage socialization, and provide mental stimulation, all of which can prevent mental deterioration and encourage a faster recovery. They also refresh the spirit and help regain energy spent healing.

**What You Need:** (Available in activities bin)

- Newspaper or news magazine
- Old photos and magazines

**What You Should Do:**

- **Discussing Current Events**
  
  This activity can help provide orientation and keep the person mentally involved in the world outside. The general principle is to initiate conversation about news events to engage and stimulate the person, while providing orientation to time, place, person, and events

  - Read a section of the paper together and review important points
  - Encourage discussion and actively listen
  - Try using questions that do not require “yes” or “no” as an answer, thereby encouraging more conversation

- **Reminiscence**

  This is a great way to get to understand a person’s experiences, encourage them to take inventory of their life, values, abilities, and to identify shared ideas. To reminisce is “to talk about the good old days.” This activity is a useful way to help people open up and feel more comfortable in stressful situations. The reminiscence activities should be used to link the past with the present, and to provide orientation and cognitive stimulation.

  - Use old photographs or magazines to talk about things from the past, and how they differ from today. For example, pictures or singers or movie stars from the past
  - Always try to link the past recollection to the present and to provide orientation
EXERCISE AND WALKING ASSISTANCE

Lack of exercise interferes with the function of major body organs and leads to generalized deconditioning including loss of muscle strength, balance, and endurance. Keeping older adults upright and walking regularly can prevent serious complications.

**Purpose:** The goal of the early mobilization program is to keep older patients physically moving while they are in the hospital. For patients that are able, walking assistance is recommended. For those who are unable to walk, simple exercise movements called active range of motion should be performed. Walking at least 2-3 times per day is essential for physical and mental well being. Walking helps to prevent loss of muscle mass and flexibility, which happens very quickly when adults are confined to bed.

**Procedure:**

1. Check with nurse to ensure older adult is able to get out of bed. The nurse may need to fix IV lines or catheters (if any) for walking.
2. Lower bed to lowest position, raise head of bed, lower side rails.
3. Assist older adult to sitting position:
   a. Ask older adult to roll onto side, slide legs to edge of bed and then lower legs over edge of bed
   b. Ask patient to push up to the sitting position by pushing the elbow of one arm and palm of the other into bed
   c. Allow patient to sit at edge of bed for a few minutes to prevent dizziness. Encourage them to pump ankles up and down to stimulate circulation
4. Help older adult put on nonskid slippers/shoes
5. Assist older adult to standing position
   a. Ask older adult to slide or scoot to edge of bed
   b. Have older adult position feet flat on the floor directly under knees
   c. Have cane or walker readily available if needed
   d. Allow older adult to stand a few minutes to gain balance. Encourage older adult to stand erect with head up, shoulders back, and back straight
6. Assist the older adult to walk:
   a. If needed, support with your arm behind the older adult’s waist
   b. Follow, walking behind and to one side
   c. Encourage older adult to walk normally, do not rush. Stay with older adult at all times
   d. Walk only as far as older adult feels comfortable. Remember to start return trip before older adult is fatigued
   e. Return older adult immediately for dizziness or weakness
7. Return older adult to bed:
   a. Have older adult stand at side of bed, near top of bed so their head can easily reach the side of the bed
   b. Ask the older adult to reach back one hand at a time to edge of the bed
   c. Bend waist, hips, and knees, and lower slowly to a sitting position
d. Have older adult scoot buttocks back so he or she is firmly seated away from the edge of the mattress

e. Once safely seated, remove slippers, and have patient swing legs back up onto bed

8. Put call bell within reach

ACTIVE RANGE OF MOTION EXERCISES

Purpose: The goal of the early mobilization program is to keep older adults physically moving while they are in the hospital. For those who are unable to walk, simple exercise movements called active range of motion exercises should be performed. When a patient is confined to bed, active ranges of motion exercises are particularly important to prevent the complications of loss of muscle tone and flexibility of muscles and joints. These exercises are simply moving muscles and joints and are not intended to be strenuous at all.

Pointers:

- The older adult should not be holding his or her breath during the exercise routine. Ask the older adult to count out loud with each repetition. By doing, this they keep breathing properly
- Each exercise should be repeated 5-10 times. Stop for complaints of severe tiring, breathlessness, or pain
- If the older adult gets dizzy moving from lying to sitting to standing, have him or her perform the ankle bend exercises before getting up
- Have the older adult sit up straight in a chair or lie as flat as comfortable in bed during exercises
- Ensure privacy by pulling the curtain or shutting the door to room. Make sure the older adult is covered enough to preserve modesty but that clothing is loose enough to permit easy motions
- Refer to attached instructions and exercise cards for each joint

Arm Lift
1. Sit up straight in a firm chair, or if necessary lie on back as flat as comfortable
2. Place an arm at side with palm down
3. Keep elbow straight and slowly lift arm as far overhead as comfortable
4. Slowly lower arm to side
5. Complete 2 cycles.
6. Repeat with other arm

Arm Over and Out
1. Sit up straight in a firm chair, or if necessary lie on back as flat as comfortable
2. Hold arm straight from side at shoulder level
3. Bend at elbow and move hand across body to touch opposite shoulder
4. Straighten elbow and move hand back out to starting position
5. Complete 2 cycles
6. Repeat with other arm

Arm Slide
1. Sit up straight in a firm chair, or if necessary lie on back as flat as comfortable
2. Relax arm at side, turn palm up with elbow straight
3. Move arm away from body and overhead as high as comfortable
4. Complete 2 cycles
5. Repeat with other arm

Shoulder Roll
1. Sit up straight in a firm chair, or if necessary lie on back as flat as comfortable
2. Arm at side, raise elbow to shoulder level
3. Roll at the shoulder to raise hands so fingers point overhead, then slowly roll shoulder so hand lowers and fingers point toward toes
4. Complete 2 cycles
5. Repeat with other shoulder

Elbow Bends
1. Sit up straight in a firm chair, or if necessary lie on back as flat as comfortable
2. With arms at side, bend at elbow so hand touches shoulder and then fully straighten the elbow
3. Complete 2 cycles
4. Repeat with other elbow

Palm Up and Down
1. Sit up straight in a firm chair, or if necessary lie on back as flat as comfortable
2. Tuck bent elbow close to waist
3. Roll the wrist to move the palm of the hand up and down
4. Complete 2 cycles
5. Repeat with other wrist

Wrist Bends
1. Sit up straight in a firm chair, or if necessary lie on back as flat as comfortable
2. Holding the rest of the arm still, bend wrist back and forth as far as comfortable
3. Complete 2 cycles
4. Repeat with the other wrist

Heel Slides
1. Lie on back as flat as is comfortable with toes pointing to ceiling
2. Bend one knee and hip, sliding foot up on bed and as close to buttocks as is comfortable
3. Straighten knee and hip, moving foot back down the bed. Repeat but lift the heel off the bed to minimize friction
4. Complete 2 cycles
5. Repeat with other leg
Hip Slides
1. Lie on back as flat as is comfortable with toes pointing to ceiling
2. Keeping knee straight, move one heel as far out to the side as comfortable. Carry the weight of the leg in the thigh, keeping heel off the bed to minimize friction
3. Return leg to starting position
4. Complete two cycles
5. Repeat with other leg

Ankle Bends
1. Sit up straight in a firm chair, or if necessary lie on back as flat as comfortable
2. Bend the ankle as far as is comfortable to point toes up
3. Slowly straighten ankle and then bend as far as is comfortable to point toes down
4. Complete 2 cycles
5. Repeat with other ankle
ENHANCING HEARING AND VISION

Purpose: To maximize hearing and vision in the older adult using environmental and communication strategies. Both hearing and vision are essential for understanding speech.

To Enhance Hearing
- Create a quiet, private environment by pulling the curtain in the room and closing the door. Turn off television or radio. This will create a sense of privacy and reduce background noise.
- If person wears hearing aid(s), make sure they are being used, and are clean and operating. Adjust if needed. Make sure batteries are working using battery tester. If they do not wear hearing aids, use the amplified hearing device available at nurse’s station.
- Pull up a chair and sit down at eye level within 1 – 1 ½ feet. Be sure they can see your lips and keep eye contact.
- Make sure your face is well lit and avoid standing with your back to the light.
- Read the daily newspaper together for at least five minutes
  - Allow your family member to pick a favorite section
  - Using the “Clear Speech Method” read one paragraph aloud at a time, pausing between
  - Ask the older adult to repeat the main points in his or her own words so you can see if they have understood the paragraph.
- Communicate using the “Clear Speech Method” by expressing every word and sentence:
  - Precisely and accurately
  - In a fully formed manner
  - Slightly slower than you typically do (which happens automatically when you attempt to be clearer)
  - Slightly louder (which happens automatically when you attempt to be clearer)
  - In a lively manner with a full range of voice intonation (tone) and stress on key words
  - Pause briefly between all phrases and sentences.
- Reinforce your speech with gestures, pointing, and touch.

To Maximize Vision
- If the person wears glasses or contacts, make sure they are clean, in place, and properly fitted.
- Make sure there is adequate lighting for the older adult to see.
- Use large-type printed materials and instructions. Aim to read together for at least five minutes.
- If the person cannot read, read the information to them. Also consider using tape recorded information or books.
• Check to make sure the person understands information by asking them to repeat the main points.

• Make sure personal items are nearby and the person can either see items or is familiar with where they are placed. For example, call bell is to the left of you in the bed, tissues are on the night stand.
APPENDIX K

FAMILY CAREGIVER TRACKING FORM

Patient:___________   Family Caregiver:___________
Date:____________   Time of Visit:_____   Room #:_____  

During your visit with your family member, please:
• Ask family member if they have any questions or concerns. Write them on your assignment sheet, and tell the nurse.
• Ensure the call bell and telephone are within reach. Assist your family member with phone calls as necessary.
• Review and update your family member, as necessary:
  Procedure(s): ________________________ Time:________
  (e.g., PT, OT, etc.) ________________________ Time:________
  Other Activity: ________________________ Time:________
• Update your family member’s nurse before leaving and review the interventions completed and communicate any concerns regarding your family member’s plan of care.

Indicate whether intervention is done or not done by checking appropriate box.
IF INTERVENTION(S) NOT DONE, PLEASE GIVE REASONS WHY AND DESCRIBE WHAT STOOD IN YOUR WAY. Remember to wake your family member before performing interventions. Please visit even if visitors are present.

Comments:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

<table>
<thead>
<tr>
<th>Intervention To Be Completed as Assigned by Researcher (Complete checked activities)</th>
<th>Instructions</th>
<th>Done/Not Done (IF NOT, WHY?)</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Orientation   Times assigned per visit: _____ 1x _____ 2X</td>
<td>• Provide orienting communication, when talking to the person</td>
<td>□ Done □ Not done</td>
</tr>
</tbody>
</table>
provide useful specific reminders of time and place

- Update your family member with: day, date/year, meal times, tests or procedures planned if known

<table>
<thead>
<tr>
<th>Therapeutic Activity</th>
<th>Assigned Activity: ______________________________</th>
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<tbody>
<tr>
<td>□ Done □ Not done</td>
<td>□ Done □ Not done</td>
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<table>
<thead>
<tr>
<th>Mobility</th>
<th>Complete twice per visit</th>
</tr>
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<tbody>
<tr>
<td>□ R. O. M. □ Walk: Room only</td>
<td></td>
</tr>
<tr>
<td>□ Walk: ½ hallway</td>
<td></td>
</tr>
<tr>
<td>□ Walk: full hallway</td>
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</tr>
<tr>
<td>□ Walk: ________</td>
<td></td>
</tr>
<tr>
<td>□ Done □ Not Done</td>
<td></td>
</tr>
<tr>
<td>Number of times_______</td>
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<table>
<thead>
<tr>
<th>Vision</th>
<th>Equipment was:</th>
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<tbody>
<tr>
<td>□ Used □ Not used</td>
<td></td>
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<tr>
<td>Intervention was:</td>
<td></td>
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<tr>
<td>□ Done □ Not Done</td>
<td></td>
</tr>
<tr>
<td>□ Done □ Not Done</td>
<td></td>
</tr>
<tr>
<td>How long? __________</td>
<td></td>
</tr>
<tr>
<td>□ Done □ Not Done</td>
<td></td>
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<tr>
<td></td>
<td>points</td>
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<tr>
<td></td>
<td>• Make sure needed items are nearby (call bell, tissues)</td>
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</table>

**Hearing**

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<tr>
<th></th>
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<tbody>
<tr>
<td></td>
<td>• Ensure hearing aid(s) in place and check batteries if used</td>
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<tr>
<td></td>
<td>• Pull up a chair and sit at eye level within 1 foot.</td>
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<tr>
<td></td>
<td>• Maintain eye contact and face person, ensuring they can see your lips, during Newspaper exercise</td>
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</tr>
<tr>
<td></td>
<td>• Newspaper exercise: Use “clear speech” method in your conversations with goal of reading a section of the newspaper aloud to the older adult</td>
<td></td>
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<tr>
<td></td>
<td>1. Express every word and sentence in a precise, accurate, and fully formed manner</td>
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<tr>
<td></td>
<td>2. Speak slightly slower than normally in a firm, medium loud, lively voice.</td>
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<tr>
<td></td>
<td>3. Use short clear sentences with stress on key words</td>
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<tr>
<td></td>
<td>• Pause between each paragraph asking the older adult to summarize what was just read</td>
<td></td>
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<tr>
<td></td>
<td>• Reinforce your speech with gestures, pointing, touch etc.</td>
<td></td>
</tr>
</tbody>
</table>

**Equipment was:**

- Used
- Not used

**Intervention was:**

- Done
- Not Done

**For how long?**

________

- Done
- Not Done
APPENDIX L
DATA COLLECTION FORMS FOR STANDARDIZED ASSESSMENTS

Admission Assessment of Patient’s Physical Function

ACTIVITIES OF DAILY LIVING (ADL)

INSTRUCTION TO INTERVIEWER:

General Instructions for responses:

2 = Without human help: The respondent needed no help to perform this function, but may have used an assistive device. (“Help” refers to assistance of a person).

1 = With some human help: The respondent was able to perform this function with the help or supervision of another person. For example, this respondent was able to shave, once another person had laid out the razor and shaving cream.

0 = Unable: The respondent was unable to perform this function, and someone else had to do it for him/her. For example, another person had to spoon-feed the respondent.

INSTRUCTIONS TO PARTICIPANT: Now I would like to ask you some questions about your everyday activities at home. For the answers to these questions, I would like to know what you can do TODAY.

1. **Today**, can you feed yourself...
   
   Without help (including cutting meat, opening containers) – 2
   
   With some help (have someone cut up food, butter bread, etc.) - 1
   
   Completely unable to feed yourself – 0

2. **Today**, can you dress and undress yourself...
   
   Without help (including cutting meat, opening containers) – 2
   
   With some help (have someone cut up food, butter bread, etc.) - 1
   
   Completely unable to feed yourself – 0
3. **Today**, can you take care of your own personal grooming...

   - Without help (including shaving, combing hair etc.) – 2
   - With some help (have someone put toothpaste on toothbrush, etc.) – 1
   - Completely unable to take care of your own personal grooming – 0

4. **Today**, can you walk...

   - Without help – 2
   - With some help (have someone hold arm for support, etc.) – 1
   - Completely unable to walk – 0

5. **Today**, can you get out of bed...

   - Without help – 2
   - With some help (have someone hold arm while standing up) – 1
   - Unable to get in and out of bed – 0

6. **Today**, can you take a bath, sponge bath, or shower...

   - Without help (including getting in and out of tub or shower) – 2
   - With some help (have someone set up bathing items, etc.) – 1
   - Completely unable to take a bath, sponge bath, or shower – 0

7. **Today**, can you use the toilet...

   - Without help – 2
   - With some help (have someone rearrange clothes etc.) – 1
   - Unable to get to the toilet (unless taken by somebody) – 0

8a. As we get older, we can have the tendency to leak urine. Does this ever happen to you?

   - Yes – 1
   - No – 0

8b. If yes, in a typical week, how often does this happen? Times ____
Total Score: _______ Questions 1-7 (0-14)
Score Question 8: _______

VISION ASSESSMENT

INSTRUCTION TO PARTICIPANT: Now, I have some questions about your vision.

No     Yes    NA

1a. Do you wear eyeglasses or contact lenses?  0  1

1b. (IF YES) Do you have your eyeglasses or contact lenses here?  0  1  9

INSTRUCTION TO INTERVIEWER:

The pocket vision screener is used to test near vision. If respondents normally wear corrective lenses, then they should be tested with their corrective lenses on first and then without them on. Verify adequate lighting and clean lenses if needed.

**Equipment**

- Pocket vision screener
- String (14”)

**Procedure**

- Interviewer holds pocket vision screener 14 inches from respondent’s eye. Measure by holding the string 14 inches to bridge of nose.
- Read the transition statement, “Now read the line that has the smallest numbers that you can see.”
- If the respondent gets more than one wrong, then go up to the next line and continue to do so until the respondent gets only one wrong or is unable to read the entire line.
- If the respondent can read the entire line without errors go to the next line lower and repeat process until the lowest line respondent can read is identified.

To score results, record the number that corresponds with the line the respondent read correctly (maximum one error). Record results.

**INSTRUCTIONS TO PARTICIPANT:** Now, I want to test your eyesight. If you wear glasses, please put (leave) them on. This string will allow me to hold the card 14 inches from your eyes. Now read the line that has the smallest numbers you can see. (IF
PATIENT CAN READ THAT LINE, GO TO THE NEXT LINE LOWER. RECORD LOWEST LINE THE PATIENT CAN READ, ALLOWING ONE ERROR.

2. Vision score = 20/____ (Corrected); 20/_______ (Uncorrected)
   Blind - 002
   Unable - 996

VISION CHART POSSIBLE SCORES

<table>
<thead>
<tr>
<th>20/20</th>
<th>20/40</th>
<th>20/100</th>
</tr>
</thead>
<tbody>
<tr>
<td>20/25</td>
<td>20/50</td>
<td>20/200</td>
</tr>
<tr>
<td>20/30</td>
<td>20/70</td>
<td>20/400</td>
</tr>
</tbody>
</table>

HEARING ASSESSMENT

INSTRUCTIONS TO PARTICIPANT: Now, I have some questions about your hearing.

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a. Do you usually wear a hearing aid(s)?</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>1b. (IF YES,), Do you have your hearing aid(s) here?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>2a. Which ear(s) do you wear a hearing aid for?</td>
<td>Right</td>
<td>Left</td>
<td>9</td>
</tr>
<tr>
<td>2b. When did you last have your hearing tested?</td>
<td>_ _ / _ _ _ _</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

INSTRUCTIONS TO INTERVIEWER:

The Whisper Test is a simple screening method for hearing impairment. If respondents normally wear hearing aid(s), they should be tested both with (first); and without them in

Equipment

- Flexible (cloth or paper) tape measure

Procedure

Conducting the whispered voice test

- The examiner stands arm’s length (0.6 m) in front of the seated patient
- The examiner whispers a combination of numbers and letters (for example, 4-K-2) and then asks the patient to repeat the sequence
The examiner should quietly exhale before whispering to ensure as quiet a voice as possible.

- Sit in front of the respondent so that you are facing them.
- Use tape measure and measure 1 foot in front of the person. Inhale deeply. Then exhale fully. At the end of the first exhale whisper the first set of numbers, “2, 6, 9.” Note: By exhaling and then whispering the set of numbers, it promotes a consistent voice tone.
- Have respondent repeat the set of numbers and record the results as correct or incorrect.
- Repeat for the next set of numbers.
- Cover your mouth so that the ability to lip read is removed.
- Inhale deeply. Then exhale fully. At the end of the first exhale, whisper the next set of numbers, “3, 5, 8.”
- Have respondent repeat the set of numbers and record the results as correct or incorrect.
- Repeat for the next set of numbers.

The patient is considered to have passed the screening test if they repeat at least three out of a possible six numbers or letters correctly for audiovisual-aided speech (mouth uncovered); and at least three out of a possible six numbers or letters correctly for purely auditory speech (mouth covered).

WHISPER TEST

INSTRUCTION TO PARTICIPANT: Now I’m going to test your hearing. I’m going to stand in front of you and whisper 3 numbers. You will try to hear what I’m saying and tell me the numbers that you hear.

<table>
<thead>
<tr>
<th>INCORRECT</th>
<th>CORRECT</th>
<th>UNABLE TO TEST</th>
</tr>
</thead>
</table>

1. “2-6-9” What are the numbers I said?

   a. “2” 0 1 6
   b. “6” 0 1 6
   c. “9” 0 1 6

2. “1-5-7” What are the numbers I said?

   a. “1” 0 1 6
   b. “5” 0 1 6
   c. “7” 0 1 6
INSTRUCTIONS TO PARTICIPANT: Now I’m going to test your hearing differently. I’m going to stand in front of you and whisper 3 numbers but I will cover my mouth. You try to hear what I’m saying and tell me the numbers that you hear.

INCORRECT       CORRECT       UNABLE
TEST

3. “3-5-8” What are the numbers I said?

   a. “3”       0       1       6
   b. “5”       0       1       6
   c. “8”       0       1       6

4. “1-9-2” What are the numbers I said?

   a. “1”       0       1       6
   b. “9”       0       1       6
   c. “2”       0       1       6

Score: (Does not wear hearing aid) *Uncovered: ___/12   Covered___/12
(Hearing aid(s) in)   *Uncovered: ___/12   Covered___/12
(Hearing aid(s) out)   *Uncovered: ___/12   Covered___/12

ADMISSION ASSESSMENT OF COGNITIVE FUNCTION

MINI MENTAL STATE EXAM (MMSE)

INSTRUCTIONS TO INTERVIEWER: This section is intended to test the respondent’s memory and concentration. It is important that the interviewer present the test exactly as written. It is also important that there be as little distraction as possible to allow the respondent to give his/her full attention to the testing. Any interruptions such as unexpected visitors or phone calls may affect results.

ORIENTATION

INSTRUCTIONS TO PARTICIPANT: I’d like to ask you some questions to check your memory. Don’t worry if you don’t know the answers. (WRITE PARTICIPANT’S ANSWERS TO ALL QUESTIONS AND GIVE ONE POINT FOR EACH CORRECT ANSWER).

CORRECT       ERROR

1. What is the year? __________________  1       0
2. What is the season? ________________  1       0
3. What is the date? ____________________ 1 0
4. What is the day of the week? ______________ 1 0
5. What is the month? ____________________ 1 0
6. Can you tell me where we are? ________________ 1 0
   (PROMPT: What is the name of this place?)
7. What city are we in? ____________________ 1 0
8. What state are we in? ____________________ 1 0
9. What county are we in? _________________ 1 0
10. What floor of the hospital are we on? ____________ 1 0
    Subtotal __ __/10

REGISTRATION

INSTRUCTIONS TO PARTICIPANT: I am going to name 3 objects. After I have
said them, I want you to repeat them. Remember what they are because I am going to ask
you to name them again in a few minutes. The three items are:

“Apple”…”Table”…”Penny”

(RECORD ANSWERS HERE BASED ON FRIST REPETITION)

<table>
<thead>
<tr>
<th>CORRECT</th>
<th>ERROR</th>
</tr>
</thead>
<tbody>
<tr>
<td>11a. APPLE</td>
<td>1</td>
</tr>
<tr>
<td>11b. TABLE</td>
<td>1</td>
</tr>
<tr>
<td>11c. PENNY</td>
<td>1</td>
</tr>
</tbody>
</table>

(REPEAT ALL THREE OBJECTS UNTIL LEARNED, UP TO 3 TIMES).

Subtotal __/3

ATTENTION AND SPELLING

INSTRUCTIONS TO PARTICIPANT: Now I am going to spell a word forwards and
I want you to spell it backwards (in reverse order). The word is “World” “W-o-r-l-d”
INSTRUCTIONS TO INTERVIEWER: Repeat spelling if necessary
Record all answers

<table>
<thead>
<tr>
<th>CORRECT</th>
<th>ERROR</th>
</tr>
</thead>
<tbody>
<tr>
<td>__D</td>
<td>1</td>
</tr>
<tr>
<td>__L</td>
<td>1</td>
</tr>
<tr>
<td>__R</td>
<td>1</td>
</tr>
<tr>
<td>__O</td>
<td>1</td>
</tr>
<tr>
<td>__W</td>
<td>1</td>
</tr>
</tbody>
</table>

Subtotal __/5

(COUNT ONLY 1 ERROR IF SUBJECT LEAVES OUT ONE LETTER, BUT SUBSEQUENT LETTERS ARE CORRECT. SCORE CORRECT IF RESPONDENT CORRECTS SELF WITHOUT PROMPTING. IF RESPONDENT GIVES 6 LETTERS, SCORE ONE ERROR AT BEGINNING OR END. IF 2 LETTERS ARE REVERSED, SCORE AS 1 ERROR ONLY).

RECALL

INSTRUCTIONS TO PARTICIPANT: Now, what are the 3 objects I asked you to remember?

<table>
<thead>
<tr>
<th>CORRECT</th>
<th>ERROR</th>
</tr>
</thead>
<tbody>
<tr>
<td>APPLE</td>
<td>1</td>
</tr>
<tr>
<td>TABLE</td>
<td>1</td>
</tr>
<tr>
<td>PENNY</td>
<td>1</td>
</tr>
</tbody>
</table>

(SCORE CORRECT EVEN IF NOT REPEATED IN ORDER LISTED)

Subtotal __/3

LANGUAGE

INSTRUCTIONS TO INTERVIEWER: (CODE ‘6’ ONLY IF PATIENT UNABLE DUE TO BLINDNESS OR PARALYSIS)

<table>
<thead>
<tr>
<th>CORRECT</th>
<th>ERROR</th>
<th>UNABLE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

14. (POINT TO WRIST WATCH)
What is this called? ____________________ 1 0 6
(WATCH’ OR ‘TIMEPIECE’
IS ACCEPTABLE, ‘CLOCK’
IS NOT)

15. (SHOW PENCIL)
What is this called? ____________________ 1 0 6

16. I’d like you to repeat a phrase after me:
“No ifs, ands, or buts.” 1 0 6
(ALLOW ONLY ONE TRIAL, SCORE CORRECT FOR AN ACCURATELY
ARTICULATED REPETITION)

17. Please read the words on this paper and
then do what it says (Show paper) 1 0 6
(SCORE CORRECTLY IF PATIENT CLOSES EYES)

INSTRUCTIONS TO INTERVIEWER: (HAND PATIENT A BLANK PIECE OF
PAPER)

INSTRUCTIONS TO PARTICIPANT: Take this paper in your right hand. Fold the
paper in half. Put the paper on the floor (or bed, IF IN BED).
(DO NOT REPEAT THE INSTRUCTIONS OR COACH. DO NOT DEMONSTRATE.
CAN SWITCH TO LEFT HAND IF PATIENT CANNOT USE RIGHT HAND).

<table>
<thead>
<tr>
<th>CORRECT</th>
<th>ERROR</th>
<th>UNABLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>18a.</td>
<td>TAKES PAPER</td>
<td>1 0 6</td>
</tr>
<tr>
<td>18b.</td>
<td>FOLDS PAPER IN HALF</td>
<td>1 0 6</td>
</tr>
<tr>
<td>18c.</td>
<td>PUTS PAPER ON FLOOR OR BED</td>
<td>1 0 6</td>
</tr>
</tbody>
</table>

19. Write a short sentence for me
(WRITE ON ATTACHED BLANK PAGE; SENTENCE SHOULD HAVE A SUBJECT
AND VERB AND MAKE SENSE)

20. Now copy the design that you see printed on
the page 1 0 6
(CORRECT IF 2 FIVE SIDED FIGURES INTERSECT TO FORM A DIAMOND)

Subtotal ___/9

MMSE: Grand Total ____/30
CLOSE

YOUR

EYES
THERAPEUTIC ACTIVITIES SCREENING

INSTRUCTIONS TO INTERVIEWER: The therapeutic activities screen helps identify the patient’s interests and provide activities to stimulate cognitive and social abilities during hospitalization.

INSTRUCTIONS TO PARTICIPANT: You will sometimes have unoccupied time while you are in the hospital and we would like to provide you with enjoyable activities to keep you physically and mentally active.

1. What is your occupation (current or past)? ______________________

2a. Do you have any routines, interests, or hobbies that we could help you continue while you are here in the hospital?
   Yes – 1
   No – 0

2b. If yes, what are they?

   Activity

   ______________________________

   ______________________________

   ______________________________

   ______________________________

   ______________________________

   ______________________________

   ______________________________

3. I am going to tell you about some additional materials that we have available in the hospital. Please tell me what you might enjoy

   Yes  No

   a. Daily newspaper ____________________  1  0
   b. Music _____________________________  1  0
   c. Books _____________________________  1  0
   d. Magazines _________________________  1  0
   e. Cards _____________________________  1  0
   f. Board games ______________________  1  0
   g. Puzzle ____________________________  1  0
   h. Arts and crafts ____________________  1  0
INSTRUCTIONS TO INTERVIEWER: Elaborate on and narrow down topics of interest. For example, if patient likes to read books, the interviewer should explore if patient prefers romance, mystery, biography, condensed version etc. Comments:
CONFUSION ASSESSMENT METHOD WORKSHEET

EVALUATOR:  
DATE:  

I. ACUTE ONSET AND FLUCTUATING COURSE

a) Is there evidence of an acute change in mental status from patient’s baseline?  
   No__  Yes__  

b) Did the (abnormal) behavior fluctuate during the day, that is tend to come and go or increase and decrease in severity?  
   No__  Yes__  

II. INATTENTION

Did the patient have difficulty focusing attention, for example, being easily distractible or having difficulty keeping track of what was being said?  
   No__  Yes

III. DISORGANIZED THINKING

Was the patient’s thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?  
   No __  Yes__

IV. ALTERED LEVEL OF CONSCIOUSNESS

Overall, how would you rate the patient’s level of consciousness?

--Alert (normal)
--Vigilant (hyperalert)
--Lethargic (drowsy, easily aroused)
--Stupor (difficult to arouse)
--Coma (unarousable)

Do any checks appear in this box?  
   No __  Yes__

If all items in Box 1 are checked and at least 1 item in Box 2 is checked a diagnosis of delirium is suggested.

APPENDIX M
FAMILY CAREGIVER QUESTIONNAIRE

Thank you for participating in a research study evaluating a program that can help to decrease the risk of your family member developing delirium while in the hospital. We would like your feedback on a number of aspects of the program in order to improve the likelihood of its effectiveness.

1. Did you feel that the manual and verbal instruction prepared you adequately to perform the intervention protocols? Yes □ No □
   • What was helpful?
   • What was not helpful?
   • Suggestions for improvement?

2. Of the activities that you were assigned, indicate how difficult each was to perform:

Orientation
Not at all difficult Slightly difficult Moderately difficult To a great extent difficult
1 2 3 4

Therapeutic Activities
Not at all difficult Slightly difficult Moderately difficult To a great extent difficult
1 2 3 4

Mobility
Not at all difficult Slightly difficult Moderately difficult To a great extent difficult
1 2 3 4

Vision
Not at all difficult Slightly difficult Moderately difficult To a great extent difficult
1 2 3 4
Hearing

Not at all difficult  Slightly difficult  Moderately difficult  To a great extent difficult

1  2  3  4

3. How would you describe the role of your family member’s nurses in supporting your participation in the program? What was helpful and/or not helpful?

4. How do you think this intervention program to prevent delirium in the older hospitalized adult might be improved?

Comments:

Study ID#: 
Thank you for participating in a research study evaluating a program that can help to decrease the risk of your developing delirium while in the hospital. We would like your feedback on a number of aspects of the program in order to improve the likelihood of its effectiveness.

1. What was it like for you to participate in the Family Participation Delirium Prevention Program?

2. How would you describe the role of your nurses in supporting you and your family caregiver’s participation in the program? What was helpful and/or not helpful?

3. How do you think this intervention program to prevent delirium in the older hospitalized adult might be improved?

Comments:

Study ID#: P__
Thank you for volunteering to complete this anonymous staff nurse questionnaire. We would like your feedback on a number of aspects of a study that is being conducted on your unit order to improve the likelihood of its effectiveness.

1. Did you find the in-service “Delirium in the older hospitalized adult” to be helpful? Yes □  No □  Did not attend □
   • What was helpful?
   • What was not helpful
   • Suggestions for improvement?

2. Were you aware that the research study entitled “Family Participation in a Delirium Prevention Program for the Older Hospitalized Adult” is being conducted on your unit? Yes □  No □

3. Were any of your older adult patients enrolled in the Family Participation Delirium Prevention Program? Yes □  No □

4. How did you find out they were enrolled?

5. Did the family caregivers approach you with questions? Yes □
   What kinds of questions did they ask?
   What was this like for you?
   No □

6. How would you describe your role in supporting family caregiver’s participation in the program? What was helpful and/or not helpful that you did?

7. How do you think this intervention program to prevent delirium in the older hospitalized adult might be improved?
# APPENDIX P

## PATIENT CARE PLAN

<table>
<thead>
<tr>
<th>NAME</th>
<th>UNIT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ROOM</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>ADMISSION DATE: <strong>/</strong><em>/</em>__</th>
</tr>
</thead>
<tbody>
<tr>
<td>DISCHARGE DATE: <strong>/</strong><em>/</em>__</td>
</tr>
</tbody>
</table>

### ORIENTATION

*MMSE: Baseline-___ Discharge-___*

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Admit</td>
<td>CAM score ___</td>
<td>O x 1</td>
</tr>
<tr>
<td>b. DATE <strong>/</strong><em>/</em>__</td>
<td>CAM score ___</td>
<td>O x 1</td>
</tr>
<tr>
<td>c. DATE <strong>/</strong><em>/</em>__</td>
<td>CAM score ___</td>
<td>O x 1</td>
</tr>
<tr>
<td>d. DATE <strong>/</strong><em>/</em>__</td>
<td>CAM score ___</td>
<td>O x 1</td>
</tr>
<tr>
<td>e. DATE <strong>/</strong><em>/</em>__</td>
<td>CAM score ___</td>
<td>O x 1</td>
</tr>
<tr>
<td>f. DATE <strong>/</strong><em>/</em>__</td>
<td>CAM score ___</td>
<td>O x 1</td>
</tr>
</tbody>
</table>

### THERAPEUTIC ACTIVITIES

Occupation: Interests: Adaptation

<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
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<th></th>
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</thead>
</table>

### MOBILITY

Overall ADL score: Baseline:___ Discharge-___

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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<th></th>
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<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>cane</td>
<td>rolling walker</td>
<td>walker</td>
<td>catheter</td>
<td>IV</td>
<td>Oxygen</td>
<td>Other</td>
</tr>
<tr>
<td>a. Admit</td>
<td>ROM</td>
<td>FRM</td>
<td>WRM</td>
<td>WHH</td>
<td>WFH</td>
<td>WTI</td>
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<td></td>
<td>VISION</td>
<td>HEARING</td>
<td></td>
<td></td>
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<td>------</td>
<td>------------------------------------------</td>
<td>-----------------------------------</td>
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<tr>
<td></td>
<td><strong>Magnifier</strong></td>
<td><strong>Baseline-R__/6     L__/6  Discharge-R__/6  L/6 hearing aid(s)  amplified hearing device</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a.</td>
<td>Admit</td>
<td>HEA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>9:NA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b.</td>
<td>DATE <strong>/</strong>/__</td>
<td>HEA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>VIS</td>
<td>9:NA</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>c.</td>
<td>DATE <strong>/</strong>/__</td>
<td>HEA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
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<td>VIS</td>
<td>9:NA</td>
<td></td>
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<td></td>
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<tr>
<td>d.</td>
<td>DATE <strong>/</strong>/__</td>
<td>HEA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>VIS</td>
<td>9:NA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e.</td>
<td>DATE <strong>/</strong>/__</td>
<td>HEA</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>VIS</td>
<td>9:NA</td>
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<tr>
<td><strong>d.</strong></td>
<td>**DATE **<strong>/</strong>/__</td>
<td>HEA</td>
<td>9:NA</td>
<td></td>
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</tr>
<tr>
<td><strong>e.</strong></td>
<td>**DATE **<strong>/</strong>/__</td>
<td>HEA</td>
<td>9:NA</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
**APPENDIX Q**

**STUDY VARIABLES AND MEASUREMENTS**

<table>
<thead>
<tr>
<th>Study Variable</th>
<th>Time of Assessment</th>
<th>Purpose/Measurement</th>
<th>Reliability/Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographics</td>
<td>Admission</td>
<td>Descriptive Medical Record</td>
<td>N/A</td>
</tr>
<tr>
<td>Patient Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
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<tr>
<td>Admitting Diagnosis</td>
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<td></td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Caregiver Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship to patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Delirium</td>
<td>Admission Daily, and Discharge</td>
<td>Descriptive CAM * criteria for delirium Based on four features: acute onset and fluctuating course (feature 1), inattention (feature 2), disorganized</td>
<td>Previously validated, with a sensitivity of 94 to 100 percent, a specificity of 90 to 95 percent, and high interobserver reliability (93%) for older hospitalized adults (Inouye et al., 1990; Laurila, Pitkala, Strandberg, &amp;</td>
</tr>
<tr>
<td>Delirium Risk Factors</td>
<td>Cognitive impairment</td>
<td>Within 24 hours of admission and at discharge</td>
<td>Descriptive MMSE § score</td>
</tr>
<tr>
<td>----------------------------</td>
<td>----------------------</td>
<td>-----------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Eleven question measure; tests five areas of cognitive functioning: orientation, registration, attention and calculation, recall, and language. Maximum score is 30, with score of less than 24 indicative of cognitive impairment</td>
</tr>
<tr>
<td>ADL impairment</td>
<td></td>
<td>Within 24 hours of admission and at discharge</td>
<td>Katz Index of ADL score« Ranks adequacy of performance in seven daily functions: feeding, dressing, grooming, walking, transferring, bathing, and toileting in addition to assessing continence; Scored for the amount of help required in each of the seven functions and for the presence of incontinence; Score of two in any function indicates complete independence; one indicates need for some assistance; and zero indicates complete dependence.</td>
</tr>
</tbody>
</table>

Shown to be reliable and valid for measurement of cognitive functioning in older adults (Bassuk & Murphy, 2003; Foreman, Fletcher, Mion, & Simon, 1996; Foreman, & Grabowski, 1992). Elhan et al. (2005) found adequate reliability (Cronbach’s alpha of 0.75), support for internal construct validity by fit of the data to the Rasch model, and support for external construct validity by correlation with cognitive disability and expected associations.

Demonstrated utility in evaluating functional status in the older adult population (Brorsson & Asberg, 1984). Reliability (Cronbach’s alpha 0.84-0.94) and content and predictive validity (Pearson correlation coefficient 0.64) have been established (Reijneveld, Spijker, & Dijkshoorn, 2007).
| Vision impairment | Complete dependence. Overall score of ten to fourteen indicates full function; five to nine indicates moderate functional impairment; and four or less indicates severe functional impairment.  
Jaeger test  
Visual impairment is defined as binocular near vision after correction worse than 20/70; Jaeger card, which has print samples of different sizes, held fourteen inches from the person’s eye to test for near visual acuity.  
Whisper test  
Whisper test used to measure hearing according to the number of twelve whispers heard after correction. 7 to 12 whispers heard indicates full hearing; 3 to 6 moderate impairment; and 2 or fewer severe impairment.  
Inouye and colleagues (1993) used the Jaeger test to screen for visual impairment in establishing a predictive model for the occurrence of delirium that included visual impairment as an independent baseline risk factor (adjusted relative risk 3.5; 95% CI 1.2-10.7). The Jaeger test has been shown to be reliable (Cronbach’s alpha, 0.85) with good predictive validity (Runge, 2000).  
Inouye and colleagues (1993) used the Whisper test to screen for hearing impairment in establishing a predictive model for the occurrence of delirium that included hearing impairment as an independent baseline risk factor (adjusted relative risk 2.0, 95% CI 0.9-4.6). Studies have established the reliability of the whispered voice test with correlations of 0.67 to 0.88 (Eekhof et al., 1996; MacPhee et al., 1988; Uhlmann, Reed, Psaty, & Duckett, 1989). Uhlman et al. (1989) confirmed good... |
|------------------|------------------------------------------------|
| Hearing impairment | Complete dependence. Overall score of ten to fourteen indicates full function; five to nine indicates moderate functional impairment; and four or less indicates severe functional impairment.  
Jaeger test  
Visual impairment is defined as binocular near vision after correction worse than 20/70; Jaeger card, which has print samples of different sizes, held fourteen inches from the person’s eye to test for near visual acuity.  
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Inouye and colleagues (1993) used the Whisper test to screen for hearing impairment in establishing a predictive model for the occurrence of delirium that included hearing impairment as an independent baseline risk factor (adjusted relative risk 2.0, 95% CI 0.9-4.6). Studies have established the reliability of the whispered voice test with correlations of 0.67 to 0.88 (Eekhof et al., 1996; MacPhee et al., 1988; Uhlmann, Reed, Psaty, & Duckett, 1989). Uhlman et al. (1989) confirmed good... |
Convergent validity of the Whisper test with standard pure tone and speech audiometry testing. It can be used for detecting both types of hearing loss and its performance compares favorably with the portable audioscope, which has a sensitivity of 87-96% and a specificity of 70-90% (Burkey, Lippy, Schuring, & Rizer, 1998).

<table>
<thead>
<tr>
<th>Intervention Completion Overall By protocol</th>
<th>Discharge</th>
<th>Daily and at Discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orientation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapeutic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early Mobilization</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hearing</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Primary outcome: Daily intervention completion will be defined as the actual number of intervention protocols completed/total number of protocols assigned. In addition, overall rates of completion for each intervention protocol will be measured as number of times completed/number of times assigned. Completion of interventions will be based on family caregiver tracking as done/not done on the Family Caregiver Tracking form.

Procedure based upon the tracking system used for the Delirium Prevention Trial, which yielded an overall adherence rate for the intervention protocols of 89% (Inouye et al., 1999); Adherence was highest for the orientation (96%), vision (93%), hearing (93%), therapeutic activities (91%), and early mobilization protocols (88%); supports the use of these protocols for the proposed study.

Evaluation to Sign Consent | Admission | Evaluation to Consent Measure Five-item questionnaire that assesses whether a subject’s factual understanding of information is sufficient to provide ethically valid consent to participate in a specific research study; five questions reflect the subject’s ability to: (1) name two Resnick et al. (2007) found adequate reliability (Cronbach’s alpha of 0.75), support for internal construct validity by fit of the data to the Rasch model, and support for external construct validity by correlation with cognitive disability and expected associations.
potential risks incurred as a result of participating in the study; (2) name two things expected of him or her related to participation; (3) explain what he or she would do if no longer interested in participating in the study; (4) explain what he or she would do if distress or discomfort was experienced associated with study participation; and, (5) explain the randomization process; Evidence of ability to sign consent is based on correct responses to all five items on the ESC.

| ¥ Not applicable | ¥ Confusion Assessment Method (Inouye et al., 1990) |
| § Mini Mental State Exam (Folstein, Folstein, & McHugh, 1975) |
| « Katz Index of Activities of Daily Living (Katz, Ford, & Maskowitz, 1963) |
| ≠ Whisper test (MacPhee, Crowther, & McAlpine, 1988) |
| £ Evaluation to Consent Measure (DeRenzo, Conley, & Love, 1998) |
APPENDIX R

BUDGET FOR ENTIRE PROJECT PERIOD

TOTAL AWARD AMOUNT: $13,224
TOTAL BUDGET AMOUNT: $12,844
Balance: $380.00

Sigma Theta Tau International Small Research Grant
Budget for Entire Proposed Project Period
Direct and Program Costs

<table>
<thead>
<tr>
<th>Categories</th>
<th>Amount Requested</th>
<th>Total Budget Amounts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personnel <em>(Requests for Investigator salaries may be included. Include hourly rate for personnel.)</em></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Secretarial staff</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Typing Costs <em>(must be those directly related to the research. Typing of dissertations will not be funded.)</em></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Research Assistants</td>
<td>271</td>
<td>0</td>
</tr>
<tr>
<td>Consultants <em>(Limit to $50 per hour)</em></td>
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<tr>
<td>Supplies</td>
<td>495</td>
<td>0</td>
</tr>
<tr>
<td>Computer Costs <em>(software only)</em></td>
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</tr>
<tr>
<td>Travel Expenses <em>(data collection only)</em></td>
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<td>0</td>
</tr>
<tr>
<td>Other</td>
<td>600</td>
<td>0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>3224</td>
<td>0</td>
</tr>
</tbody>
</table>

**Justification**

*Supplies:* Anticipated direct program costs for the proposed study are based upon those established for the HELP Program, modified for the smaller scale and purpose of this study. These will include costs for equipment and supplies for the orientation and therapeutic activities protocols (CD players with head sets, 4@$20.00; 1920’s and 1930’s CD’s, 4@$15.00; reminiscence card sets, 3@$15.00; large printed reading materials,
4@$28.00); early mobilization protocol (walkers, 2@$40.00; canes, 2@$15.00) and visual and hearing protocols (magnifying lenses, 6@$8.00; audioamplification devices, 1@$40.00).

**Computer Costs:** Funds are requested for memory sticks to back up all stored data (10@$30.00) and the SPSS software for data analysis ($200.00)  

**Travel:** Travel consists of 35 miles for one way to Massachusetts General Hospital for five days per week during data collection at mileage rate for MGH for FY 2007 (.485/mile) (Faculty fellowship grant/MGH Institute of Health Professions will fund return trip)  

**Other:** Funds are requested for a pager for rental (1@$25.00/month X 4 months) for the principal investigator so that the unit administrative assistant can page with any new older adult admissions.

**MGH Institute of Health Professions Faculty Fellowship Award/Geriatric Research 2008**  
**Budget for Entire Proposed Project Period**  
**Direct and Program Costs**

<table>
<thead>
<tr>
<th>Category</th>
<th>Cost</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary/stipend</td>
<td>$1,731/month X 3 months</td>
<td>$5,193.00</td>
</tr>
<tr>
<td>Supplies:</td>
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</tr>
<tr>
<td>1. Daily newspaper</td>
<td>2 per day X 5 days/week @ 0.75</td>
<td>$120.00</td>
</tr>
<tr>
<td>2. Family training supplies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manuals (20)</td>
<td>20 @ $27.50</td>
<td>$550.00</td>
</tr>
<tr>
<td>Computer expenses</td>
<td></td>
<td></td>
</tr>
<tr>
<td>QSR NVIVO07</td>
<td>1 @ $495.00</td>
<td>$495.00</td>
</tr>
<tr>
<td>Laptop</td>
<td>1 @ $500.00</td>
<td>$500.00</td>
</tr>
<tr>
<td>Travel</td>
<td>35 miles/day x 5days/16weeks @ .485/mile</td>
<td>$1,358</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Remuneration for Participants (10)</td>
<td>10 X $50.00</td>
<td>$500.00</td>
</tr>
<tr>
<td>Graduate Research Assistant/Data collection</td>
<td>5 hours/week X 16 weeks @ $11.30/hr</td>
<td>$904.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Total direct costs</strong>=$9,620.00</td>
</tr>
</tbody>
</table>
$380.00 balance

Justification

Salaries and wages:

Principal investigator (PI): The principal investigator, Deborah Rosenbloom-Brunton, will have primary responsibility for this study, including the scientific development. Salary will include a stipend salary for the PI at the current fiscal year NRSA predoctoral stipend level (in FY2007 this is $20,772 per year; see http://grants.nih.gov/training/nrsa.htm#policy); for the three summer months of July-August, 2008 and June, 2009, during which the PI will work on the study at 1.00FTE. During the other months of the study, the PI will maintain her 1.00 FTE (10 month position) at the MGH-IHP, while working on the program 0.20, as the standard allotted time for faculty research. The PI has demonstrated the ability to carry this load over the past two years as she completed her doctoral coursework and worked at 1.00 FTE at the MGH Institute of Health Professions.

Graduate Research assistants: A Bullfinch temp, who is a graduate assistant from the MGH-IHP, will be utilized to assist with data collection (older adult screening, family caregiver training) at the 2007 rate of $11.30/hr for a total of 5 hours per week during the 16 weeks of data collection.

Materials and Supplies

Anticipated direct program costs for the proposed study are based upon those established for the HELP Program, modified for the smaller scale of this feasibility study. These will include two daily newspapers at a rate of 0.75 each during the 16 weeks of data collection for the therapeutic activities protocol.

Supplies will also be needed for the manuals for training of family caregivers in the intervention protocols.

Computer

Funds are requested for a laptop for data collection ($500.00) and to purchase QSR NVivo07 for qualitative data analysis.

Other

Funds of $50.00 per participant are requested as compensation for family caregivers’ parking fees.

Travel

Travel will consist of 35 miles one way to Massachusetts General Hospital from Manchester, NH for five days per week during data collection (4 months) at mileage rate for MGH for FY 2007 (.485/mile).
StatisticalConsultation/Resources
In addition to the statistical resources provided by both the MGH Biostatistics Center and The Biostatistics Consulting Center at UMASS Amherst as discussed in the Facilities and Resources section, the PI will meet with an unpaid statistical consultant from the MGH Institute of Health Professions faculty member who teaches the Biostatistics course in the DNP Program, at the half point and upon completion of data analysis, to provide additional support for statistical analysis, interpretation of the results, and collaboration on grant writing for future external funding.
## APPENDIX S

### TIMELINE

<table>
<thead>
<tr>
<th>Date</th>
<th>4/07-8/08</th>
<th>1/08-3/08</th>
<th>7/08-8/08</th>
<th>8/08-9/08</th>
<th>9/08-12/08</th>
<th>1/09-4/09</th>
<th>4/09-5/09</th>
</tr>
</thead>
<tbody>
<tr>
<td>Design FPDPP</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Pilot FPDPP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
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</tr>
<tr>
<td>In-service nursing staffs on study units</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Train research assistants</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>

| Specific Aim 1 (track intervention completion) | | | | | | | |
| Data Acquisition | X | | | | | | |
| Data entry and cleaning | | X | | | | | |
| Data entry and cleaning | X | | | | | | |

| Specific Aim 2 (identify barriers and facilitators) | | | | | | | |
| Data Acquisition | X | | | | | | |
| Data Analysis | X | | | | | | |

| Specific Aim 3 (role of nurse support) | | | | | | | |
| Data Acquisition | X | | | | | | |
| Data Analysis | X | | | | | | |

| Final Report | X | | | | | | |


REFERENCES


Coulter, M. A. (1999). The needs of family members of patients in intensive care units. *Intensive Care Nursing, 5*(1), 4-10.


