INFORMAL CAREGIVER DETECTION, RECOGNITION, AND REPORTING OF SYMPTOMS OF
DELIRIUM IN HOSPITALIZED OLDER ADULTS WITH DEMENTIA

A Dissertation in
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by
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ABSTRACT

Background: Delirium is common, costly, and leads to adverse consequences in hospitalized older adults. Pre-existing dementia is the most common risk factor for the development of delirium. Despite multidimensional interventions aimed at improving outcomes, delirium superimposed on dementia remains poorly detected and recognized by formal healthcare providers. Informal caregivers are proposed as a viable solution to improve detection and recognition in this vulnerable population.

Purpose: The purpose of this study is to systematically assess informal caregiver recognition, detection, and reporting of symptoms of delirium in hospitalized older adults with pre-existing dementia.

Methods: Quantitative and qualitative data were collected in this descriptive, exploratory work from 38 informal caregiver and patient dyads. This study was embedded within a National Institutes of Nursing Research funded cluster, randomized controlled clinical trial, Early Nurse Detection of Delirium Superimposed on Dementia (END-DSD). In addition to data collected within this study, an additional informal caregiver post-hospitalization telephone interview was conducted (N=23).

Results: Although there was poor agreement between researcher and informal caregiver ratings of full and subsyndromal delirium, there was 100% agreement on delirium features of acute change and inattention. These are two hallmark features of delirium. Results from the qualitative data explore the acute care experience for informal caregivers of persons with pre-existing dementia and suggest that delirium occurs and persists across transitions of care.

Conclusion: Informal caregivers appear to be a source of information in the acute care setting to improve detection and recognition of delirium superimposed on dementia. This group needs to be considered in research and practice as a critical component of the transdisciplinary healthcare team.
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“We ourselves feel that what we are doing is just a drop in the ocean. But the ocean would be less because of that missing drop.”

Mother Teresa
Chapter 1

Introduction

Delirium is an acute disturbance in cognitive functioning often occurring in adults over the age of 65 years. Persons with pre-existing dementia are at a high risk for the development of delirium (Fick, Agostini, & Inouye, 2002). Delirium is associated with adverse events including higher rates of rehospitalization, increased risk of institutionalization, higher rates of cognitive and physical decline, and increased rates of morbidity and mortality (Eeles et al., 2010; Fong et al., 2012; Han et al., 2009). In the acute care setting delirium significantly increases healthcare costs (Leslie & Inouye, 2011). Delirium superimposed on dementia (DSD) occurs when a person with a pre-existing dementia develops delirium (Fick, et al., 2002). These persons experience worse outcomes and cost nearly twice as much to care for as those with dementia alone (Fick, Kolanowski, Waller, & Inouye, 2005). Despite the large personal and economic burden of delirium, there remains an increased need to improve the recognition, detection, and management of delirium in the acute care system and across settings of care.

There are multiple factors impacting the recognition, detection, and management of delirium in older adults. First, routine screening for delirium using a standardized instrument is not standard in the acute care system or across settings of care (Fick, Hodo, Lawrence, & Inouye, 2007; Inouye, Foreman, Mion, Katz, & Cooney, 2001). Despite advances in practice, research, and policy, delirium remains difficult to detect due to the fluctuating nature of the syndrome. Lastly, delirium is frequently attributed to dementia, depression, or other syndromes such as sundown syndrome (Fick, Hodo, et al., 2007; Yevchak, Steis, & Evans, 2012).

Practice, research, and policy have focused on improving the detection, recognition, and management of delirium as a mechanism to improve healthcare outcomes and lower healthcare costs associated with the syndrome. With regards to improving detection and recognition, attention has been
given to the label of delirium and the use of the term (Steis & Fick, 2012), as well as implementing evidence-based, multidimensional interventions aimed at delirium management (Greer et al., 2011). Although there has been some success in improving outcomes associated with delirium, the focus has been on formal healthcare providers. To date, practice, research, and policy have largely ignored informal caregivers as partners in care (Coleman et al., 2013), across settings of care and with vulnerable populations, such as those with dementia. There is a need to involve informal caregivers as active members of the healthcare team to improve recognition, detection, and management of delirium in persons with dementia in the acute care setting. The purpose of this study is to begin to fill this gap by systematically assessing informal caregiver recognition, detection, and reporting of symptoms of delirium in hospitalized older adults with pre-existing dementia.

**Statement of the Problem**

Prompt recognition, detection, and management of delirium are critical to improving outcomes in persons with dementia. Delirium superimposed on dementia occurs in up to 89% of adults over the age of 65 years across settings of care (Fick, et al., 2002); and delirium is a known complication of hospitalization for persons with dementia (Caplan & Rabinowitz, 2010). This syndrome is increasingly important as the number of individuals with dementia increase, considering the difficulty in recognition and detection in the highly vulnerable population (Fick & Foreman, 2000).

Adults over the age of 65 with dementia, who also develop delirium during an acute care hospitalization, are receiving attention in practice, research, and policy due to the short and long-term consequences of delirium (Torpilliesi, Bellelli, & Trabucchi, 2010; Vasilevskis & Ely, 2012; Voyer, Richard, Doucet, & Carmichael, 2011). They experience an increased risk of mortality and morbidity (Bellelli et al., 2007), as well as experience lasting functional and cognitive decline, longer lengths of acute care hospitalizations, and are more likely to be discharged to an institutional setting (Fong, et al., 2012; Fong
et al., 2009). These personal impacts of delirium superimposed on dementia lead to significant healthcare system burdens, including nursing time and overall cost. This is a vulnerable group needing and deserving of practice, research, and policy guiding changes to improve recognition, detection, and management. The change suggested in this study is the addition of informal caregivers as critical stakeholders during an acute care hospitalization.

**Recognition and Detection of Delirium by Formal Healthcare Providers**

Delirium remains a serious problem for formal healthcare providers in the acute care setting, often going unrecognized. Although healthcare providers state delirium is common in hospitalized older adults, they are not likely to systematically and routinely assess for it (Flagg, Cox, McDowell, Mwose, & Buelow, 2010). A study by Inouye et al. (2001) found that older adults within the acute care system were less likely to be recognized as having delirium if they were over the age of 80 years or had vision and/or hearing impairments. These older adults are the most vulnerable to delirium.

There are features of delirium that may make it more difficult for formal healthcare providers to recognize delirium, including the fluctuating nature of delirium; overlap of symptoms between dementia, delirium, and depression (Inouye, 2006a); and the motoric subtype of hypoactive delirium (Meagher, Moran, Raju, Gibbons, et al., 2008). Hypoactive delirium, one motoric subtype, is characterized by a decreased interaction with the environment and is often attributed, by formal healthcare providers, to a normal consequence of aging (Fick, Hodo, et al., 2007). Delirium is incredibly complex.

There have been several attempts to improve recognition and detection of delirium in the acute care setting. Multidimensional interventions have aimed to prevent delirium through routine and systematic screening for the syndrome, as well as implementation of non-pharmacological interventions targeting delirium risk factors, such as hydration, nutrition, ambulation, cognitive stimulation, sensory
impairments, and sleep (Greer, et al., 2011; Inouye, Bogardus, Baker, Leo-Summers, & Cooney, 2000). Interventions have also emphasized the need for formal healthcare provider education and interdisciplinary, geriatric-focused management of patients at high risk for delirium (E. R. Marcantonio, J. M. Flacker, R. J. Wright, & N. M. Resnick, 2001; Milisen et al., 2001; Siddiqi et al., 2011; Vidán et al., 2009). To date, the bulk of research has focused on multidimensional interventions delivered by formal healthcare providers and few are specific to persons with pre-existing dementia. There is a critical need to extend recognition, detection, and management efforts to informal caregivers in the acute care setting (Coleman, 2011; Coleman, et al., 2013).

**Recognition and Detection of Delirium by Informal Caregivers**

Involvement of informal caregivers in the recognition and detection of delirium in persons with dementia in the acute care setting has not been fully explored. Informal caregivers are able to recognize subtle symptoms indicative of delirium in persons with dementia (Fick & Foreman, 2000). Fick and Foreman (2000), in an exploratory study, found that all informal caregivers interviewed recognized an abrupt change in mental status that went unrecognized by formal healthcare providers. In addition, sixty-four percent of informal caregivers in this study stated that a physician did not speak with them regarding mental status, indicating the need to emphasize reporting of symptoms of delirium between informal caregivers and formal healthcare providers. Similar findings have been found in a different population, persons with advanced cancer (Bruera et al., 2009). This study attempts to build upon this body of knowledge to fill a gap.

Research has incorporated informal caregivers in the management of delirium to a larger extent, but still does not acknowledge the capacity of informal caregivers to be partners with delirium care. In addition, no studies have targeted informal caregivers of persons with pre-existing dementia. Some research has included this population, but has not been the target population. To date, most research
involves informal caregivers delivering a component of a multidimensional intervention, such as encouragement of informal caregivers at the bedside; assistance with activities of daily living by informal caregivers; or the delivery of the Hospital Elder Life Program (HELP) (Benedict et al., 2009; Cole et al., 2002; Li et al., 2003; D. Rosenbloom-Brunton, E. Henneman, & S. K. Inouye, 2010b). Research has also emphasized the delivery of education on delirium in a written format to informal caregivers (Gagnon, Allard, Gagnon, Mérette, & Tardif, 2010; Gagnon et al., 2002). The bulk of this work has been conducted with informal caregivers of persons with advanced cancer.

Summary: Statement of the Problem

Recognition, detection, and management of delirium by formal healthcare providers in persons with pre-existing dementia are poor in the acute care setting. Informal caregivers may improve delirium care for this vulnerable population by improving recognition and detection of symptoms of delirium (Fick, Hodo, et al., 2007) and through the reporting of their unique knowledge to formal healthcare providers (Fick & Foreman, 2000). To date, no research has systematically investigated this identified gap in knowledge.

Purpose of the Study

This descriptive, exploratory study investigates informal caregiver detection and recognition of symptoms of delirium in older adults with pre-existing dementia; identifying patient and informal caregiver characteristics related to reporting of delirium symptoms by the informal caregiver; and describes the hospital experience for informal caregivers of persons with pre-existing dementia and delirium. For the purpose of this study, informal caregivers are defined as any individual who has a significant relationship with the hospitalized elder and plays a key role in their care outside of the acute care setting, but is not a professional or paid healthcare provider (Schumacher, Beck, & Marren, 2006). The following specific aims will guide this study:
**Specific Aim 1:** To compare the agreement between informal caregiver assessment of delirium, the Family Confusion Assessment Method (FAM-CAM) to trained research assistant (RA) assessment of delirium using the Confusion Assessment Method (CAM) in hospitalized older adults with underlying dementia.

**Specific Aim 2:** To evaluate factors associated with reporting of symptoms of delirium by informal caregivers, including: dementia stage; delirium severity; delirium motoric subtype; relationship between the informal caregiver and care recipient; living arrangement between the informal care caregiver and care recipient; education level of the informal caregiver; and pre-existing knowledge of or experience with delirium.

**Specific Aim 3:** To describe the hospital experience, and the detection and recognition of symptoms of delirium, from the perspective of informal caregivers of persons with pre-existing dementia.

**Conceptual Framework**

The conceptual framework that underlies the proposed study is guided by prior research on delirium, dementia, and dementia symptom recognition by both formal healthcare providers and informal caregivers (Figure 1). Recognition of symptoms is process oriented and involves contextual factors of the environment, situation, and individuals (Steis, Penrod, Adkins, & Hupcey, 2009). Detection and recognition of delirium by informal caregivers can be related to situational awareness, which can be related to impact on patient outcomes (Fore & Sculli, 2013).

Delirium remains under-recognized and poorly detected in the most vulnerable patient population, persons with pre-existing dementia (Fick & Foreman, 2000). Delirium in this group may be attributed to normal consequences of aging (Fick, et al., 2002) or related to the underlying diagnosis of dementia (Fick, Hodo, et al., 2007; Morandi et al., 2011), involving both recognition and situational
awareness of delirium. Systematic and routine assessments, using a standardized measure for delirium, are not done in acute care (Flagg, et al., 2010). Delirium superimposed on dementia is difficult to detect (Fick, Hodo, et al., 2007) due to the fluctuating nature of the syndrome (Inouye, 2006a). Formal healthcare providers, such as registered nurses, have previously been the focus of improving detection and recognition of delirium due to their significant presence at the bedside (Inouye, et al., 2000; Milisen, et al., 2001), yet this proposal hypothesizes that they lack the knowledge of the individual and their baseline mental status to accurate identify an acute change and fluctuating course. It is also hypothesized in this proposal that Informal caregivers are critical to providing this knowledge, aiding in detection and recognition of delirium.

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Outcome</th>
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<tbody>
<tr>
<td>Characteristics of the informal caregiver and of the person with dementia may impact recognition and detection:</td>
<td>Agreement, or degree of disagreement, between informal caregiver and trained research assistant on delirium recognition and detection in hospitalized older adults</td>
</tr>
<tr>
<td>Informal Caregivers: Gender, education, relationship to older adult with dementia, living arrangement, knowledge of or experience with delirium</td>
<td></td>
</tr>
<tr>
<td>Person with Dementia: Dementia stage, delirium severity, and delirium motoric subtype</td>
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Figure 1.1 Conceptual Framework of Informal Caregiver Recognition and Detection of Delirium in Persons with Dementia

Research suggests that there are characteristics of the informal caregiver and of the person with dementia that may impact recognition and detection of delirium. Characteristics of the informal were gleaned from the literature surrounding informal caregiver detection and recognition of symptoms of
dementia (Arai, Arai, & Zarit, 2008; Hamilton-West, 2010; Hodgson & Cutler, 2003; Lehmann, 2010; Okura, 2011). Dementia was chosen because of the overlap in symptoms between dementia and delirium. To date there is no literature examining the influence of informal caregiver characteristics impacting delirium recognition in any patient population.

Characteristics of the informal caregiver that may impact delirium recognition, detection, and reporting of symptoms include the following: relationship to the older adult with dementia, living arrangement between the older adult and the informal caregiver, educational level, and previous experience or knowledge of delirium. These factors have not been explored with regard to informal caregiver recognition and detection of delirium, but have been in recognition and detection of dementia. Relationship includes both spousal and parent/adult child relationships, with spousal being considered to be more influential in recognition of dementia symptoms (Norton, 2009). In regard to living arrangement, informal caregivers who have more familiarity with the individual either by living with them or seeing them frequently are more likely to recognize symptoms of dementia (Lehmann, 2010; McLoughlin, Cooney, Holmes, & Levy, 1996; Okura, 2011). Educational level positively impacts recognition of symptoms of dementia and will likely positively influence recognition of delirium (Carpentier, Bernard, Grenier, & Guberman, 2010; Rovner, Casten, Arenson, Salzman, & Kornsey, 2011). Knowledge of or familiarity with Alzheimer’s disease improves recognition of symptoms (Hodgson & Cutler, 2003; Werner, 2003). Knowledge of a certain illness has also positively impacted symptom recognition in several other illnesses, including acute stroke, making this a potential factor in the recognition of delirium symptoms (Cytryn, Yoskowitz, Cimino, & Patel, 2009; Hsia et al., 2011; Ratner et al., 2006; Zerwic, Young Hwang, & Tucco, 2007).

In addition to characteristics of the informal caregiver, several characteristics of the person with dementia may impact recognition. Disease severity has been associated with symptom and illness recognition (Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999). Dementia stage has the potential to
impact recognition. Persons in the later stages of dementia, compared to those in the earlier stages, exhibit more behavioral and cognitive disturbances (MacDonald, Grand, & Caspar, 2011; Tschanz et al., 2011) leading to the attribution of delirium symptoms to those of the underlying dementia (Lövheim, Sandman, Karlsson, & Gustafson, 2008). Persons who exhibit more symptoms of delirium, measured as delirium severity, would be more likely to have symptoms recognized. Delirium motoric subtype has been well documented to influence recognition in formal healthcare providers. Persons who exhibit symptoms of hypoactive delirium are less likely to be recognized as delirious compared to individuals experiencing hyperactive delirium (Fick, Hodo, et al., 2007; Mittal et al., 2011).

Summary: Conceptual Framework

Formal healthcare providers poorly recognize delirium in hospitalized older adults with pre-existing dementia. The conceptual framework for the proposed study is based on research regarding recognition of symptoms of dementia and delirium; and identifies several influencing characteristics of the informal caregiver and the hospitalized older adult with dementia. The primary outcome in this study is informal caregiver recognition of delirium in hospitalized persons with dementia.

Theoretical Definitions

The following definitions were used in this study:

**Delirium:** Delirium is an acute state of confusion characterized by inattention and disorganized thinking (Inouye, 2006a). According to the American Psychiatric Association (APA) *Diagnostic and Statistical Manual, Fifth Edition* (DSM-V) criteria, delirium is defined as a disturbance in level of consciousness and an inability to maintain or direct attention (American Psychiatric Association, 2013).

**Dementia:** Dementia is a broad, progressive decline in cognitive function leading to changes in social or occupational status (Groves et al., 2000). The key features of dementia are deterioration in cognitive and functional abilities over a period of time (Payne et al., 1998). According to the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) of the American Psychiatric Association
(2013), there are 3 main criteria for the diagnosis of dementia (1) memory impairment, (2) cognitive disturbances in at least one other area of functioning, and (3) that the impairments must be severe enough to interfere daily life.

**Delirium Superimposed on Dementia:** Delirium superimposed on dementia (DSD) occurs when a person with a pre-existing dementia develops delirium (Fick, Hodo, et al., 2007).

**Demographic Variables:** Characteristics or attributes of the population of interest, including but not limited to, age, gender, diagnosis, education, and race.

**Detection:** To discover or detect that something is present or exists (Merriam-Webster’s, n.d.). In this case, it refers to informal caregiver detection of symptoms of delirium.

**Formal Healthcare Providers:** Professional, paid healthcare staff including, but not limited to, physicians, registered nurses, licensed practice nurses, certified/non-certified nursing assistants, physical therapists, occupational therapists, speech therapists, and social workers/case managers.

**Informal Caregiver:** An individual with a close, significant relationship to the hospitalized older adult in this study (Schumacher, et al., 2006). This individual may provide assistance with activities of daily living outside of the acute care setting, including dressing, eating, and bathing (Clipp & Moore, 1995), but is a non-paid caregiver.

**Recognition:** The act of acknowledgment; or a special notice of feeling (Merriam-Webster’s, n.d.).

Recognition is process-oriented, resulting in a response (Steis, Penrod, Adkins & Hupcey, 2009). The response to recognition of changes is not necessarily an action or intervention and depends on the contextual or environmental constraints placed on recognition in a specific situation or condition.

**Recognition Accuracy:** The comparison between a gold standard and informal measurement of a certain attribute or condition, in this case referring to comparisons ratings of delirium in persons with pre-existing dementia between a research assistant and informal caregiver.
**Subsyndromal Delirium:** Having one or more symptoms of delirium, but not having the full syndrome of delirium (Cole, McCusker, Dendukuri, & Han, 2003).

**Assumptions**

The following assumptions will be made in this study:

1. Delirium occurs frequently in hospitalized older adults.
2. Dementia is the greatest independent risk factor for the development of delirium in hospitalized older adults.
3. Delirium in persons with pre-existing dementia is under-recognized by formal healthcare providers within the acute care setting.
4. Informal caregivers recognize acute mental status changes in persons with pre-existing dementia.
5. Multidimensional interventions aimed at improving recognition of delirium by professional healthcare providers should include informal caregivers as a member of the healthcare team to be more effective.
6. Characteristics of the informal caregiver and hospitalized person with dementia impact recognition of delirium symptoms.

**Significance of the Study**

This study has significant clinical implications impacting the recognition and assessment for delirium. The main focus of this study is to further understand the recognition of delirium, including the particular symptoms associated with delirium, by informal caregivers. Currently there is a lack of information regarding systematic recognition of delirium in hospitalized older adults with dementia. This study will contribute to filling that current gap in knowledge. This study will also impact communication between informal and formal caregivers by illustrating how and when informal caregivers communicate with formal caregiver regarding changes in memory and thinking, and symptoms of delirium.
Summary: Chapter 1

Delirium frequently occurs in hospitalized older adults, particularly those with pre-existing dementia, resulting in large personal and economic burdens. Despite the negative consequences of delirium, it remains under-recognized in hospitalized older adults. Several multidimensional, and one-dimensional, interventions have been developed and tested to improve formal caregiver recognition of delirium in the acute care setting with some success. Interventions have also included informal caregivers to enhance prevention and management of delirium in the acute care setting. Currently, there are no studies that have systematically examined informal caregiver recognition of symptoms of delirium in persons with pre-existing dementia. In addition, few studies have looked at the reporting of these symptoms between informal and formal caregivers within the acute care setting. The purpose of this study is to further understand informal caregiver recognition and detection of delirium in older adults with pre-existing dementia; identifying patient and informal caregiver characteristics related to recognition in this population; and explore the process by which symptoms of delirium are communicated between informal and formal caregivers in the acute care setting.
Chapter 2

Review of the Literature

Delirium is highly prevalent among hospitalized older adults, leading to poor outcomes including increased risk of mortality and morbidity, higher rates of institutionalization, and lasting functional and cognitive decline (Bellelli, et al., 2007; Fick, et al., 2002; McCusker, Cole, Dendukuri, Belzile, & Primeau, 2001). Delirium superimposed on dementia (DSD) occurs when an individual with pre-existing cognitive impairment develops delirium. DSD also results in longer lengths of stay in the acute care setting (Boustani et al., 2010) and higher economic and personal burden for hospitalized older adults and their informal caregivers. Research has demonstrated that persons with DSD or delirium alone cost nearly twice as much to care for as persons without dementia or delirium (Fick, et al., 2005). A more recent study by Leslie and colleagues estimates that the national cost of delirium to the health care system is as high as $152 billion annually (Leslie, Marcantonio, Zhang, Leo-Summers, & Inouye, 2008). Despite the large burden, delirium remains largely undetected in hospitalized older adults with dementia (Boustani, et al., 2010; Fick & Foreman, 2000; Han, et al., 2009).

Delirium superimposed on dementia is poorly detected in the acute care setting for a number of reasons. First, formal healthcare providers do not routinely conduct cognitive or mental status assessments (Boustani, et al., 2010; Fick & Foreman, 2000; Flagg, et al., 2010). In addition, formal healthcare providers are not aware of the significance of delirium, particularly in persons with pre-existing dementia (Inouye, 2006a). Despite recent research elucidating the significance of delirium superimposed on dementia, formal healthcare providers continue to need additional education and training to detect, recognize, and manage delirium in the acute care setting (Steis, Shaughnessy, & Gordon, 2012; Young, Hinami, Arseven, Jain, & Williams, 2012). Potentially due to a lack of education and training, formal healthcare providers attribute signs and symptoms of delirium in persons with pre-existing dementia to worsening of the dementia, depression, or sundown syndrome (Fick, Hodo, et al.,
Lastly, critical symptoms of delirium, such as the fluctuating nature of the syndrome, make it difficult for formal healthcare providers to detect and recognize (Inouye, 2006a). In contrast to formal healthcare providers, informal caregivers may be able to detect and recognize symptoms of delirium superimposed on dementia, despite a lack of education and training, as well as the course of delirium, due to their baseline knowledge of the individual (Bond, 2009; Fick, et al., 2002).

Informal caregivers, defined for the purpose of this review as any non-paid, individual having a significant relationship with the hospitalized older adult with dementia, want to be involved with care and included as a member of the healthcare team (P. Black, Boore, & Parahoo, 2011). In their role as informal caregiver, the individual provides assistance with activities of daily living, independent activities of daily living, as well as emotional support (Barbosa, Figueiredo, Sousa, & Demain, 2011). Providing assistant with these types of activities on a routine basis allows the informal caregiver to develop knowledge of baseline cognitive status, particularly in persons with pre-existing dementia.

Evidence supports this assertion in informal caregivers who are able to detect and recognize cognitive changes indicative of dementia, prior to a formal diagnosis (Haley, Clair, & Saulsberry, 1992; Hayes, Zimmerman, & Boylstein, 2010). To date there is one study that supports informal caregiver detection and recognition of delirium in persons with pre-existing dementia (Steis et al., 2012). This study was conducted within the context of home healthcare. Although there is a paucity of literature regarding informal caregiver detection and recognition of delirium superimposed on dementia, there is support that informal caregivers are able to detect and recognize delirium in persons with advanced cancer diagnoses (Bruera, et al., 2009; Gagnon, et al., 2002; Vidán, et al., 2009).

The following literature review will present and synthesize evidence regarding: 1) the relationship between dementia and delirium; 2) detection and recognition of delirium in hospitalized older adults with pre-existing dementia; 3) tools used to detect dementia, delirium, and delirium
superimposed on dementia; 5) multidimensional interventions used to improve detection, recognition, and management of delirium in persons with and without dementia 5) involvement of informal caregivers in interventions; and 6) potential factors impacting detection and recognition of delirium in persons with pre-existing dementia. This review of the literature, in addition to the conceptual framework, will provide the foundation for the proposed study.

Dementia and Delirium: Distinct and Closely Linked

Dementia and delirium are distinct medical diagnoses and clinical syndromes, yet they are closely linked. The following section of this review will include significance, definition, subtypes, symptoms, predisposing and precipitating factors, etiology, and management of dementia and delirium, as well as a discussion of delirium superimposed on dementia. This review is critical to understanding distinctions between dementia and delirium, as well as commonalities, which will provide the foundation for detection and recognition of delirium in persons with pre-existing dementia by informal caregivers.

Dementia

Dementia is a global term referring to lasting, progressive, and generalized decline in thinking and memory, that lead to changes in social or occupational functioning (Groves, et al., 2000; Jablonski, 2013). Dementia is prevalent and places a large burden on individuals, formal healthcare providers, informal caregivers, and the general healthcare system. Recent research estimates the prevalence of dementia in the United States in 2010 to be 17.4% of adults over the age of 70 years (Alzheimer’s Association, 2010; Hurd, Martorell, Delavande, Mullen, & Langa, 2013). Dementia potentially affects up to 30% of adults over the age of 85 years in the United States (Zarit & Zarit, 2007). Annually, dementia is estimated to cost as much as $215 billion (Hurd, et al., 2013). The global term of dementia refers to a syndrome, not a disease.
**Definition.** The fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) (2013), defines criteria for diagnosis the syndrome of dementia as a disturbance in memory and one other area of cognitive functioning, severe enough to impact daily life (Association, 2013; Hurd, et al., 2013). Additional disturbances in cognitive functioning for a diagnosis of dementia include the following: 1) agnosia, 2) apraxia, 3) aphasia, or 4) executive function (Holsinger, Deveau, Boustani, & Williams, 2007). Agnosia is an impaired ability to recognize familiar objects. Impairment in motor abilities is referred to as apraxia. Aphasia refers to an alteration in the ability to communicate. Executive function is the ability to plan, coordinate, and initiate complex activities, including but not limited to those associated with occupation activities or maintaining a household (American Psychiatric Association, 2013; Holsinger, et al., 2007). Differential diagnoses include: depression, delirium, mild cognitive impairment, medication side effects, thyroid disease, vitamin deficiencies, and the abuse or overuse of alcohol or drugs (Emre, 2009; Hurd, et al., 2013).

**Symptoms.** Dementia is a progressive disorder, leading to lasting cognitive and functional impairments (Payne, et al., 1998). Persons with dementia may also experience a change in personality (Zarit & Zarit, 2007). Additional symptoms of dementia include a change in visuospatial abilities. Dementia often manifests first as an inability to learn and process new information; over time the ability to perform everyday tasks, such as grooming, bathing, dressing, and eating is lost (Zarit & Zarit, 2007). Dementia has additional symptoms or features dependent on type and etiology.

**Dementia Subtypes.** For the purpose of this review, and to gain a better understanding of the subtypes of dementia, the main types will be briefly identified, including: 1) Alzheimer’s disease, 2) vascular dementia, 3) Lewy body and Parkinson’s disease dementias, and lastly, 4) frontotemporal dementia (Alzheimer's Association, 2010; Jablonski, 2013; Zarit & Zarit, 2007). Recent evidence suggests
that dementia primarily is a mixed subtype, particularly in adults over the age of 80 years (Hurd, et al., 2013).

Alzheimer’s disease is the most common cause of dementia (Zhu & Sano, 2006) and is characterized by progressive loss in memory and cognitive function, as well as the inability to learn new information. Persons with Alzheimer’s disease typically experience multiple stages of loss in memory and cognitive, as well as physical, functioning. Vascular dementia, the second most common cause of dementia, is harder to characterize (S. E. Black, 2011; Jablonski, 2013). Symptoms are dependent on the area of the brain impacted. In addition to changes in cognitive function, symptoms may include, but are not limited to the following: change in ambulation, differences in speech, and new urinary incontinence (Jablonski, 2013). Lewy body (LBD) and Parkinson’s disease (PDD) dementias are difficult to distinguish between based on symptomatology alone. Individuals with LBD and PDD experience some of the following symptoms often seen in persons with Parkinson’s disease: shaking, rigidity, impaired ability to focus and maintain attention, visuospatial issues, inability to plan or organize, and persistent visual hallucinations (Association, 2013). Frontotemporal dementia (FTD) is the final subtype reviewed here. In contrast to other types of dementia, FTD can occur starting at a younger age and has distinctly different features. FTD may be misdiagnosed or attributed to a psychiatric disease (Massimo & Grossman, 2008). Symptoms of FTD include: apathy, change in speech, alteration of personality, impaired judgment in social situations, lack of inhibition, and inappropriate behaviors (Shagam, 2009). Etiologies of the above common causes of dementia will be reviewed in the next section.

Etiology. Dementia etiology can be categorized as either primary or secondary. Primary dementias, also referred to as degenerative dementias, include: Alzheimer’s disease, DLB, PDD, dementia associated with Huntington’s disease, multiple system atrophy, corticobasal degeneration, and multiple others (Emre, 2009). Secondary dementias are those that occur in conjunction with
another disease or condition, but result in dementia-like symptoms. The symptoms occur due one of the following disease processes: 1) direct damage to brain tissue or structure; 2) change in brain pressure or shape; or 3) inability of brain cells to function correctly (Emre, 2009). First, direct damage to brain tissue or structure may be a result of vascular disease (e.g., stroke, transient ischemic attack), trauma, post-radiation, and brain tumors. Tumors, hematomas, and normal pressure or structure hydrocephalus may result in change of brain pressure or shape. Finally, certain conditions cause brain cells to inappropriately function or to cease function resulting in dementia symptoms. These include metabolic and endocrine disorders, nutritional deficiencies, systemic immune-mediated or inflammatory conditions, or introduction of toxins (i.e., poisons, alcohol, drugs, heavy metals, dialysis) (Association, 2013; Emre, 2009; Zarit & Zarit, 2007).

The etiology of primary dementias will be briefly presented. This is by no means a full exploration of the etiology and research regarding main dementia types. The majority of primary dementias are resultant from an interaction of genetic, baseline and lifestyle factors, and environmental conditions (Shagam, 2009). Alzheimer’s disease is thought to be a result of beta-amyloid plaque accumulations and neurofibrillary tau protein tangles. This is also seen in FTD, but with an emphasis on frontal and side brain regions (Shagam, 2009). There is no distinct etiology of FTD known at this time. Accumulations of alpha-synuclein proteins in the cortex of the brain result in DLB while accumulations of the same proteins in the substantia nigra result in PDD (Association, 2013).

**Management.** Management and treatment of dementia is based on etiology and cause, detailed presentation of management and treatment strategies for primary and secondary dementias is beyond the scope of this review. Overall, there is concurrent use of both pharmacological and non-pharmacological strategies to manage and treat dementias and their associated symptoms. At the
present time there is a large amount of research being done to better manage and treat dementia, primarily Alzheimer’s disease (Association, 2013).

Delirium

In contrast to dementia, *delirium* is an acute change in cognitive function, characterized by a change in attention and an altered level of consciousness (Inouye, 2006a). Delirium occurs frequently in persons over the age of 65 years and dementia is the leading risk factor for the development of delirium (Inouye, 1999). Delirium occurs across settings of care and commonly occurs in hospitalized older adults (Inouye, 2006). The prevalence of delirium in acute care is estimated to be 42-56% (Fong, Tulebaev, & Inouye, 2009; Siddiqi, House, & Holmes, 2006). Like dementia, delirium is costly in both personal and economic burden. Delirium is estimated to cost the United States healthcare system $152 billion annually (Leslie & Inouye, 2011).

**Subtypes.** Delirium has been categorized according to the following three main subtypes: hyperactive, hypoactive, and mixed (Liptzin, 1992; Meagher & Trzepacz, 2000). An additional delirium subtype, normal/mild delirium, has also been identified, but is not frequently used as a category in research and practice (Yang et al., 2009). For the purpose of this review, and the proposed study delirium will be categorized according to the three main subtypes.

Delirium subtypes were initially categorized according to their characteristics and presence of key symptoms of delirium (Liptzin, 1992). Liptzin and Levkoff (1992) used a cohort of 325 hospitalized older adults, assessing them daily for symptoms associated with delirium to identify key features of hyperactive and hypoactive delirium. From this foundational work, hyperactive delirium was defined as having a minimum of four of the following features: hypervigilance, restlessness, loud or fast speech, irritability or anger, combativeness, impatience, uncooperative, swearing, singing, laughing, wandering, euphoria, easy startling, distractibility, nightmares or persistent thoughts. Hypoactive delirium was
defined as having four or more of the following symptoms: decreased alertness, slowed speech, lethargy, unawareness, slowed motor movement, staring, or apathy (Liptzin, 1992). Mixed delirium was defined as meeting criteria for both hyperactive and hypoactive delirium (Liptzin, 1992).

Research defining and categorizing delirium has continued using the study by Liptzin & Levkoff as a starting point. Hyperactive delirium has more recently been redefined as a change in baseline over the past 24 hours including at least two of the following symptoms: increased quantity of motor activity, loss of activity control, wandering, and/or restlessness (Meagher, Moran, Raju, Leonard, et al., 2008). Addition features of hyperactive delirium may include agitation, aggression, hypervigilance, and hyperalertness (Meagher & Trzepacz, 2000; Mittal, et al., 2011). Hypoactive delirium is defined as a definite change from baseline over a 24 hour period with decreased speed and/or amount of activity, and at least one of the following additional symptoms: reduced environmental awareness, decreased amount and/or speed of speech, lethargy, withdrawal, and reduced alertness (Meagher, Moran, Raju, Leonard, et al., 2008). Mixed delirium occurs when there are symptoms of both hyperactive and hypoactive delirium present within a 24 hour period (Meagher, Moran, Raju, Leonard, et al., 2008). It is also realistic to have no delirium motoric subtype identified. These definitions will be used in this review and proposal to define hyperactive and hypoactive delirium.

Delirium motoric subtypes have a significant role in the detection and recognition of delirium, particularly in persons with pre-existing dementia. Hospitalized older adults with hyperactive delirium; due to symptoms such as wandering, restlessness, and agitation associated with this motoric subtype, often require increased attention and care from formal healthcare providers (Meagher, Moran, Raju, Leonard, et al., 2008). Hyperactive delirium is associated with increased use of physical and chemical restraints. The increase in care and the use of restraints makes hyperactive delirium more likely to be attended to by formal healthcare providers (Voyer, Cole, McCusker, St-Jacques, & Laplante, 2008).
Hypoactive delirium, on the other hand, is less likely to be recognized, although it is the most common subtype of delirium in persons with pre-existing dementia (Fick, et al., 2002; Fick, Hodo, et al., 2007). It is frequently misdiagnosed or attributed to a depressive illness or dementia (Fong, Tulebaev, et al., 2009; Inouye, 2006a; Mittal, et al., 2011). Hypoactive delirium is associated with worse outcomes, particularly in persons with pre-existing dementia (Yang, et al., 2009); highlighting the need to identify acute cognitive changes, such as increased amounts of sleep and decreased interaction with the environment, associated with hypoactive delirium.

**Symptoms.** Delirium is associated with symptoms beyond those presented when describing hyperactive, hypoactive, and mixed subtypes of delirium (Bond, 2009; Inouye, 2006a). An acute change is the main distinction between dementia, which is progressive and occurring over longer periods of time, and delirium. In addition, key features of delirium as identified by the Confusion Assessment Method, include: fluctuating course, inattention, disorganized thinking, and altered level of consciousness (Inouye et al., 1990b). Further features of delirium, across subtypes, have been identified as: visual and auditory hallucinations and/or delusions, altered sleep/wake cycles, disorientation, disturbances in sensory function, changes in mood or behavior, apathy, and agitation (Gupta, de Jonghe, Schieveld, Leonard, & Meagher, 2008; Inouye, 2006a). Given these symptoms, it is clear that there is an overlap between dementia and delirium.

**Etiology.** According to DSM-IV criteria, delirium is dependent on an underlying acute or chronic medical condition (American Psychiatric Association, 2013). The etiology of delirium is complex and involves not only an underlying condition, but also an interaction between predisposing and precipitating factors (Inouye, 1999; Lipowski, 1987); which have also been identified as moderating and mediating factors (J. Franco et al., 2010). Inouye et al. (1999) conducted foundational work in the identification of predisposing and precipitating factors using a multifactorial model developed from two
prospective cohorts; the first as a predictive cohort and the second as a validative cohort (Inouye, 1999). Additional work has been done in this area to identify predisposing and precipitating factors across populations and settings of care.

Factors that increase the risk of development of delirium are labeled as predisposing. The main predisposing factor for the development of delirium includes pre-existing cognitive impairment, i.e., dementia (Fick, et al., 2002). Persons with baseline respiratory disease also have an increased risk for delirium (Khan et al., 2012). Additional predisposing factors include advanced age and depression. Use of certain medications, such as anticholinergics, and abuse or overuse of toxins such as alcohol also influences risk for delirium (Khan, et al., 2012).

Precipitating events or insults are those that lead to the development of delirium (Inouye, 1999). Precipitating events include acute illness or an exacerbation of a chronic condition, with individuals having more chronic conditions being more predisposed (Khan, et al., 2012). Acute illness includes fall, fracture, hypertension or hypotension, hypoxia, shock, infection, metabolic disturbances (i.e., hyponatremia, hypocalcemia), and fever. Chronic conditions include pre-existing renal or liver disease, neurologic disease, history of stroke or head trauma, and persons with a terminal illness (Inouye, 2006a). Malnutrition and dehydration are precipitating events to delirium. Additional precipitating events include the use of physical restraints and invasive devices, such as intravenous lines or urinary catheters (Inouye, 2006a). Surgery is also a precipitating event (Milisen, et al., 2001). Medication use is a frequent precipitator of delirium, particular central nervous system active medications, including lorazepam, morphine, and dopamine (Han, et al., 2009; Khan, et al., 2012).

**Management.** Treatment of delirium is based on the underlying medical cause. Ideally treatment of the cause will result in delirium resolution, but recent research has expanded the convention that delirium is an entirely transient syndrome (Fong, Tulebaev, et al., 2009). Delirium,
particularly in persons with pre-existing dementia, has been demonstrated to cause lasting cognitive and functional decline (Cole et al., 2012; Gross et al., 2012). A recent study found that delirium persisted in older adults after admission to a post-acute care facility for up to one month (Anderson, Ngo, & Marcantonio, 2012). This evidence adds emphasis to the need to appropriately manage delirium, starting first with prevention.

Prevention is the first line of defense in most situations and evidence suggests prevention is the preferred form of delirium management (Inouye, et al., 2000). To date, effective delirium prevention strategies have focused on possible predisposing and precipitating events. Starting with formal healthcare providers, geriatric focused consultation, specialized delirium or acute care for the elderly (ACE) units, and nurse-driven strategies aimed at assessment for delirium have been used in the acute care setting (Greer, et al., 2011; Khan, et al., 2012). Maintaining homeostasis with chronic conditions and prevention of acute illness is another emphasis in delirium prevention, including maintaining nutrition and hydration, to prevent metabolic disturbances. In addition, avoidance of drugs known to precipitate delirium is a prevention strategy. Modification of the environment to include adequate lighting and avoiding the use of invasive devices when possible is another option, as well as, use of sensory aides such as glasses or hearing aides (Khan, et al., 2012). Currently, research is being done into pharmacological prevention of delirium, including the use of antipsychotic medications such as haloperidol or risperidone (Zhang et al., 2013).

The second component of management of delirium is treatment, which includes non-pharmacological and pharmacological strategies aimed at mitigating the cause of delirium if it is known. Non-pharmacological management strategies also use formal healthcare providers, in particular nurses, to routine detect and recognize symptoms of delirium. Also management of the individual and the environment are critical. Examples of this include use of glasses and hearing aides, promotion of
cognitive and physical activity, treatment of pain, and maintaining a routine sleep/wake cycle (S. Inouye et al., 1999; Inouye, 2006a; Khan, et al., 2012; E. Marcantonio, J. Flacker, R. Wright, & N. Resnick, 2001). This also includes removal of any invasive devices. Pharmacological management includes the judicious use of antipsychotic medications; avoidance of the class of drugs called benzodiazepines, including lorazepam, is recommended (Khan, et al., 2012).

A review of delirium provides the background into understanding the significance of this syndrome for hospitalized older adults, as well as differentiating it from dementia. The significance of each has been presented; a review of the relationship between delirium and dementia will expand on this foundation.

Delirium Superimposed on Dementia

It is well established that the most significant predisposing factor to the development of delirium is pre-existing cognitive impairment (i.e., dementia) (Inouye, 2006a). The prevalence of delirium in persons over the age of 65 years, with pre-existing dementia, ranges from 32% to 89% across settings of care (Fick, et al., 2002). Statistics provide backing that this is an important phenomenon and warrants attention in research and clinical practice. Given the complex nature of dementia and delirium when independent of each other, it is justifiable that strategies for detection, recognition, and management of delirium in persons with pre-existing dementia are more complex (Fick & Foreman, 2000).

Definition. Delirium in a person with pre-existing dementia is also known as delirium superimposed on dementia (DSD) (Fick, Hodo, et al., 2007). The true extent of the relationship between dementia and delirium has not been fully defined. To date there is evidence to suggest that delirium may be a precipitating event for the development of dementia, but work needs to be done in this area (Khan, et al., 2012). To help establish that relationship, and to fully understand for the purpose of understanding the significance of delirium superimposed on dementia, it is critical to review outcomes.
**Subtypes.** Delirium superimposed on dementia also included the three previously identified subtypes of delirium: hyperactive, hypoactive, and mixed (Meagher & Trzepacz, 2000). The hypoactive delirium subtype, which is associated with the most adverse outcomes, is frequently seen in persons with pre-existing dementia (Fick, Hodo, et al., 2007).

**Etiology.** At baseline, Torpilliesi et al. (2010) found that individuals who develop DSD are more vulnerable. Using a sample of over 2,300 older adults with dementia alone, delirium alone, or delirium with dementia they determined that certain factors predispose an individual to the development of delirium superimposed on dementia. Age, similarly to delirium alone, is a risk factor for DSD. Persons who were malnourished or who were more dependent on other for activities of daily living were more likely to have DSD. Also those with multiple chronic, comorbid conditions were the most likely to have DSD (Eeles, et al., 2010; Torpilliesi, et al., 2010). In general, individuals who are the most frail are most likely to develop delirium (McCusker, et al., 2001). This leads to the increased risk for poor cognitive and functional outcomes.

**Outcomes.** Delirium is four times more likely to occur in individuals with pre-existing cognitive impairment (J. Franco, et al., 2010). Adverse outcomes are more common in individuals with DSD compared to those with dementia or delirium alone (Torpilliesi, et al., 2010). Outcomes of delirium superimposed on dementia include individual and outcomes for the larger healthcare system.

Personal outcomes include lasting cognitive and functional decline. As stated previously, understanding the relationship between delirium and subsequent development of dementia has not been full explored, but there is data to suggest delirium accelerates the rate of cognitive decline. Using a sample of over 400 older adults, with approximately 8.8% developing delirium, Fong et al. (2009) demonstrated that persons with an episode of delirium experience increased rates of cognitive decline compared to those without delirium. Saczynski et al. (2012) had similar findings in a total prospective
sample of 225 adults over the age of 60 years undergoing cardiac surgery, 103 of who developed delirium. This study demonstrated significant cognitive decline in those who developed delirium postoperatively, with continued cognitive improvement seen as long as six months after surgery. This study did not assess for dementia presence at baseline, but it does demonstrate the lasting impact of delirium in a vulnerable population. An additional study by Gross, Jones, Habtermeriam, et al. (2012), using a prospective cohort of 263 older adults with pre-existing Alzheimer’s disease, found an increased rate of cognitive decline up to five years after delirium during an acute care hospitalization. Delirium has lasting and profound cognitive effects in persons with pre-existing dementia.

Earlier it was presented that the goal of delirium management is to promote resolution of delirium. Considering the more tenuous relationship between delirium and development of dementia, it must be considered whether cognitive decline associated with delirium during an acute care hospitalization is a new cognitive decline or persistent symptoms of delirium (Mathews, Arnold, & Epperson, 2013). Delirium has been linked to new onset dementia. A study by Davis et al. (2012) found that in a cohort of slightly greater than 550 older adults over the age 85 years, delirium was a risk factor for development of dementia.

Rather than new onset dementia, another explanation is that delirium remains and is mistaken for symptoms of dementia given the significant overlap in symptoms between the two. Persistent delirium is defined as delirium that is unresolved and it has been linked to poor cognitive and functional outcomes, as well as increased mortality risk (Cole, Ciampi, Belzile, & Zhong, 2009; Kiely et al., 2009). Up to 50% of delirium persists after an acute care hospitalization (Alici, 2012). The concept of persistent delirium remains controversial given that by definition delirium is an acute, recoverable syndrome (Cole, 2010).
Adding to this confusion about delirium and dementia is the differential diagnosis of depression. A recent study by Witlox, Slor, Jansen, et al. (2013) demonstrated that adults over the age of 75 years who had delirium after hip fracture in the acute care setting, were more likely to exhibit signs or symptoms of depression at three-month follow-up. There is additional research to be done in this area (Slor et al., 2013).

In addition to cognitive outcomes, delirium superimposed on dementia is associated with lasting functional decline as well (Witlox et al., 2010). Persons with delirium superimposed on dementia also experience longer lengths of acute care stay (Lang et al., 2010) and an increased risk for discharge to a post-acute care or institutional setting (Fong, et al., 2012; Inouye, Rushing, Foreman, Palmer, & Pompei, 1998; Kales, Kamholz, Visnic, & Blow, 2003). DSD also increases risk of morbidity and mortality (Leslie, et al., 2008; Voyer, McCusker, Cole, & Khomenko, 2006). Delirium superimposed on dementia is a burdensome and significant syndrome for older adults.

The economic impact of delirium superimposed on dementia is also significant. Cost estimates, using retrospective claims data, demonstrated that individuals with DSD were twice as costly to care for than those with dementia or delirium alone (Fick, Kolanowski, & Waller, 2007). Considering the personal impact of DSD, it is reasonable to state that persons with DSD are also more costly due to longer lengths of acute care stay and admissions to post-acute and long-term care.

Management. The goals in managing delirium superimposed on dementia are similar to those of delirium alone. First is to identify and treat the cause of delirium. Next, prevention of further cognitive and functional decline by promoting optimal function and safety is critical (Flanagan & Fick, 2010). In addition, management of any secondary complications, such as a pressure ulcer, is important. Lastly, management must emphasize prevention through monitoring for reoccurrence and resolution of
delirium symptoms. This includes not only the patient, but also formal healthcare providers and informal caregivers across settings of care.

**Summary: Dementia and Delirium: Distinct and Closely Linked**

*Dementia* is distinguished from delirium with regards to the acute, fluctuating nature of delirium compared to the long-term persistence of dementia. Both are common, particularly in older adults with the acute care setting, and lead to lasting adverse cognitive and functional outcomes. Given the outcomes of dementia and delirium, there are also significant social and economic burdens. There is a complex relationship between dementia and delirium, with the two being able to occur simultaneously. The nature of this relationship has not been fully explored. The significance of delirium superimposed on dementia leads to the critical need for improving detection, recognition, and management of this syndrome, particularly in acute care where it is most commonly seen.

**Improving Detection, Recognition, and Management of Delirium in Persons with Dementia**

Despite the adverse events and burden associated with delirium, the syndrome continues to be poorly recognized in the acute care setting. The purpose of this section is to understand current detection and recognition of delirium superimposed on dementia by formal healthcare providers; this will be followed by tools used to detect and recognize delirium superimposed on dementia, as well as a discussion of factors impacting detection and recognition by formal healthcare providers. The role of formal healthcare providers in improving detection, recognition, and management of delirium superimposed on dementia will be highlighting by providing a summary of current multidimensional interventions and their effectiveness.

Informal caregivers, important members of the transdisciplinary healthcare team, will be presented as a mechanism to improve detection and recognition of delirium in persons with pre-existing
dementia. Current tools for informal caregivers to recognize and detect DSD will be presented, as will potential factors impacting recognition and detection. Lastly, since this is a new area for research and practice, interventions aimed at improving delirium detection and recognition across populations will be presented.

Detection and Recognition of Delirium in Persons with Dementia by Formal Healthcare Providers

For the purpose of this review, formal healthcare providers include all members of the transdisciplinary healthcare team, including, but not limited to physicians, registered nurses, licensed practical nurses, nursing assistants, physical/occupational/recreational therapists, social workers or case managers, etc. Research has also examined the recognition of delirium beyond nursing staff, which will be highlighted first.

An early study by Laurila et al. (2004) wanted to understand how transdisciplinary healthcare providers detected, recognized, and distinguished between dementia and delirium. The sample included over 200 patients over the age of 70 years in an acute care setting (Laurila, et al., 2004). Eight-eight patients had a diagnosis of dementia, 77 had delirium, and 50.6% had DSD (Laurila, et al., 2004). Formal healthcare providers documented cognitive impairment in a majority of the health records, but the actual diagnoses was not provided, nor were details of the cognitive examination. Nurses in this study more readily identified symptoms of delirium compared to physicians (Laurila, et al., 2004), perhaps due to their frequent presence at the bedside. Results from this study must be interpreted with caution, but it does suggest that formal healthcare providers are detecting and recognizing delirium superimposed on dementia, but unaware of how to label it.

Difficulty of formal healthcare providers in the detection and recognition of delirium and delirium superimposed on dementia has been documented by others. Fick and Foreman (2000) conducted a descriptive, exploratory study in three phases over a twelve-month period with total of 20
hospitalized older adults and their informal caregivers. No physician or nurse in this study was observed or documented as conducting an assessment of cognitive status, yet the prevalence of delirium was 30% and subsequence incidence was 60% (Fick & Foreman, 2000). The prevalence of DSD was 89%, incredibly high. In addition, delirium was seen as unresolved in this study, and many older adults were discharged with symptoms of undetected and unrecognized delirium. Results from research indicate the common occurrence and pervasiveness of DSD, yet the lack of detection and recognition by formal healthcare providers, including nurses even though they are positioned to more aptly detect and recognize DSD due to their significant bedside presence (Inouye, et al., 2001).

Further research in this area has explored nurse documentation of delirium symptoms in persons with and without pre-existing dementia. A study by Voyer et al. (2008) specifically reported on nurse language surrounding delirium and cognitive assessment. In addition, this work also explored factors related to the accuracy of nurse documentation (Voyer, et al., 2008) with a sample size of 226 hospitalized adults over the age of 65 years with a mean age of 82. Overall results support statements regarding poor detection and recognition of delirium and DSD, particularly in persons with hypoactive delirium (Voyer, et al., 2008). Also Voyer et al. (2008) found vague documentation. Almost 24% of patient charts included documentation of confusion, while confusion or altered level of consciousness was reported in almost 50% of the medical charts. One surprising finding from this study was that delirium was more likely to be recognized in persons with multiple comorbid conditions (Voyer, et al., 2008). A significant limitation of this work was the use of the tool that does not assess for key symptoms of delirium, such as inattention or disorganized thinking.

Similarly work was done more recently and published in 2012 (Steis & Fick). This work specifically focused on the accuracy of registered and licensed practical nurse detection and recognition of delirium superimposed on dementia. The final patient population included 104 hospitalized older
adults with dementia, among which 53 also developed delirium (Steis & Fick, 2012). There was no documentation of the term delirium by nurses in this study; however, in patients who had DSD nurses were twice as likely to document the term confusion. The term confusion is not specific to delirium, or to healthcare. Nurses did document symptoms of delirium such as increased lethargy, fluctuating mental status, delusion, and restlessness (Steis & Fick, 2012). Results indicate that nurses in this study were able to detect symptoms associated with DSD, but did not label it as delirium. Results from this study must be cautiously interpreted because it included only one study site in central Pennsylvania. This does, however, provide evidence supporting the need for improved detection and recognition of delirium superimposed on dementia in acute care.

**Summary: Detection and recognition of delirium in persons with dementia by formal healthcare providers.** Delirium superimposed on dementia is poorly detected and recognized by formal healthcare providers in the acute care setting. Recent research has also demonstrated that physicians and nurses document symptoms indicative of delirium, but are not recognizing what to properly label the syndrome. There are many factors that impact this process.

**Factors Impacting Recognition and Detection of Delirium in Persons with Dementia by Formal Healthcare Providers**

Due to the acute onset and fluctuating nature of delirium it is difficult for formal healthcare providers to detect and recognize, this is even more apparent in persons with pre-existing dementia. Delirium detection and recognition is impacted by several factors, including patient and formal healthcare provider and system factors. These will be briefly reviewed to describe the difficulty detecting and recognizing delirium superimposed on dementia.

**Patient factors.** Patient factors impacting detection and recognition of DSD are considered to be dementia and delirium severity, as well as subtype. Generally, patients with pre-existing dementia are
less likely to have delirium detected and recognized by formal healthcare providers (Inouye, 2006a). Inouye, Foreman, Mion, Katz, & Cooney (2001) looked at paired ratings between researchers and registered nurses in over 790 patients over the age of 70 years, with a total of 2,721 paired ratings. Individuals with pre-existing dementia were almost three times as likely to have undetected delirium by nurses (Inouye, et al., 2001). The risk for poor detection and recognition increases with the severity of the underlying dementia.

It is established that delirium motoric subtype (i.e., hyperactive, hypoactive, and mixed) impacts outcomes, but it also influences detection and recognition. A 2007 (Fick, Hodo, et al.) study sought to assess nurse knowledge and recognition of DSD and delirium motoric subtypes using standardized case vignettes and a general test of geropsychiatric knowledge. A convenience sample of 29 registered nurses from an academic medical center participated in this study and attended an educational in-service. Eight-three percent of nurses in this study were correctly able to identify dementia, with only 41% able to identify delirium (Fick, Hodo, et al., 2007). Only 21% of nurses identified hypoactive delirium superimposed on dementia. Interestingly, nurses in this study were knowledgeable regarding geropsychiatric issues, measured using the Mary Starke Harper Aging Knowledge Exam (MSHAKE) (Santo-Novak, 2001), yet they attributed hypoactive DSD to a normal consequence of aging in this study (Fick, Hodo, et al., 2007). Although this study may not be generalized to a larger context due to its small sample size, it does support the assertion that additional education and training is needed for acute care formal healthcare providers.

**Formal healthcare provider and system factors.** In addition to patient factors, several factors of the formal healthcare provider and the health system may make delirium superimposed on dementia more difficult to detect and recognize. First, formal healthcare providers often are not familiar with delirium (Inouye, 1994). The significance of this syndrome is poorly understood and so are the adverse
events associated with it. In addition, formal healthcare providers may not understand that delirium occurs in conjunction with dementia. Symptoms of delirium may be misattributed to dementia, depression, or sundown syndrome due to a lack of knowledge (Fick, Hodo, et al., 2007).

Interesting work by Flagg et al. (2010) found that acute care staff nurses do not routinely assess for delirium unless symptoms were present, although they identified delirium as common (Flagg, et al., 2010). This finding is particularly disconcerting since delirium symptoms are not routinely detected or recognized (Flagg, et al., 2010), particularly in the most vulnerable patient populations. There is a need for increased formal healthcare provider education and training at all levels, including institutional, local, regional, and national. In addition to education, there is a need for institutions to implement routine assessment and screening protocols for delirium across settings of care.

Another health care system issue is consistent use of the term delirium. In electronic health records, delirium has been referred to by other terms or phrases, including, but not limited to: acute confusion, recoverable cognitive dysfunction, postoperative confusion, and metabolic encephalopathy (Steis & Fick, 2012). Consistent use of the term delirium is critical for improved detection and recognition.

**Summary: Factors impacting recognition and detection of delirium in persons with dementia by formal healthcare providers.** Patient factors include the nature of delirium and severity of delirium as well as pre-existing dementia. Additional formal healthcare provider and system level factors impacting detection and recognition of DSD include lack of education and knowledge, poor protocols for screening and assessment, and confusing use of terminology. Several tools have been developed to promote detection and recognition in the acute care health system and beyond.

**Formal Healthcare Provider Tools for Detection and Recognition of Delirium in Persons with Dementia**
Delirium in persons with dementia is difficult to detect and recognition. Delirium can be measured using a multitude of bedside instruments in the acute care setting. A recent systematic review found that the Global Attentiveness Rating (GAR), Memorial Delirium Assessment Scale (MDAS), Confusion Assessment Method (CAM), Delirium-Rating Scale Revised-98 (DRS-R-98), Clinical Assessment of Confusion-A (CAC), and Delirium Observation Screening Scale (DOSS) all had a high likelihood of diagnosing delirium when compared to DSM-IV criteria (Wong, Holroyd-Leduc, Simel, & Straus, 2010). For the purpose of further understanding how to detect and recognize delirium, these instruments, along with the NEECHAM Confusion Scale, and their relevance to clinical practice will be discussed.

The GAR measures attention in hospital older adults, a key symptom of delirium (Inouye, 2006a; O’Keeffe & Gosney, 1997). The GAR is based on having a conversation of approximately two minutes in length, with the older adult patient. The conversation does not include any formal testing of attention, but focuses on overall interaction between the patient and assessor during this period of conversation (O’Keeffe & Gosney, 1997). The GAR is then scored based on a 10 centimeter (cm) visual analog scale, with higher scores indicating increased attentiveness and an ability to interact in conversation, with lower scores meaning less attentiveness and less interaction in conversation. Validation on this delirium measure was undertaken by comparing the ratings to Diagnostic and Statistical Manual, 3rd edition revised (DSM-III-R) criteria of delirium and dementia, administration of the MMSE, chart review, and interview with the physician and hospital nursing staff. This portion determined whether the individual had dementia, delirium, or delirium superimposed on dementia. After this distinction was determined, four separate tests of attention were administered including: Digit Span Forwards (DSF), Digit Span Backwards (DSB), Vigilance ‘A’ test (VAT), and a timed Digit Cancellation Test. A total of 87 hospitalized older adults were included in this study, with 14 having delirium, 17 having dementia, and 4 having delirium superimposed on dementia (O’Keeffe & Gosney, 1997). Results demonstrate that all tests of
attention, except for DSF, were significantly correlated with the GAR for attention (O'Keeffe & Gosney, 1997).

The MDAS is a clinician-rated scale designed to quantify the severity of delirium (Breitbart et al., 1997). The 10-item, 4-point scale has a range from 0 to 30, and is based on DSM criteria for delirium including assessing for level of consciousness and evaluating several areas of cognitive function. Examples include asking the patient the date, month, day, year, season, floor, name of hospital, city, state, and country to assess for disorientation. The MDAS also includes an item to assess disorganized thinking, which focuses on asking the patient a complex question, such as “Describe your current medical condition” (Breitbart, et al., 1997, p. 136). The intention is for this tool to be used to measure delirium severity change over time (Breitbart, et al., 1997). The initial validation study included 33 hospitalized persons with cancer or acquired immunodeficiency syndrome (AIDS). Seventeen patients met the DSM-III-R and DSM-IV criteria for delirium, while 8 persons met the same criteria for dementia (Breitbart, et al., 1997). In this study the MDAS had a sensitivity of 70.6% and a specificity of 93.8% and a negative predictive power of 75.0%; it was correctly able to identify only 12 of the 17 delirious persons. A second validation study included 51 persons hospitalized for cancer or AIDS and compared the MDAS to the Delirium Rating Scale (DRS), MMSE, and the Clinician’s Global Rating of Delirium Severity and Delirium Type (Breitbart, et al., 1997). MDAS scores were significantly correlated with all other measures of delirium used in this study. Based on these validation studies, the MDAS is considered to be a reliable and valid measured of delirium severity in acutely ill hospitalized individuals.

The CAM was developed as a way for non-psychiatric clinicians to quickly detect delirium in at-risk individuals (Inouye et al., 1990a). The CAM was developed using DSM-III-R criteria for delirium. In addition, the algorithm used in the CAM was developed based on previous literature and expert opinion. Delirium is detected using the following CAM criteria: 1) acute onset and fluctuating course, with 2)
inattention, and either 3) disorganized thinking or 4) altered level of consciousness (Inouye, et al., 1990a). The validation study included 56 patients at two hospital sites, with a total of 26 patients having delirium and 30 without delirium, ranging in age from 65 to 92. The CAM was compared to the MMSE, Visual Analog Scale for Confusion, and the digit span. Patients with dementia, depression, or other illness causes altered mental status were purposefully included in the validation study. The CAM had a sensitivity of 100% at the first site, and 94% at the second site, with a specificity of 95% and 90%, respectively (Inouye, et al., 1990a). Based on the above validation study, the CAM algorithm was determined to be a useful measure for assessing for delirium in vulnerable, hospitalized individuals. The CAM has been further validated using multiple clinicians as the assessors, including nurses and research assistants, as well as in selected populations, such as persons on the intensive care units or those with mechanical ventilation (Ely et al., 2001; Gaudreau, Gagnon, Harel, Tremblay, & Roy, 2005; Pompei, Foreman, Cassel, Alessi, & Cox, 1995).

The DRS-R-98 is a 16-item clinician-rated scale with 13 items measuring delirium severity and 3 items indicating diagnosis (Trzepacz et al., 2001). The maximum score of the DRS-R-98 is 46 points, with a maximum severity score of 39 points; each item is scored on a scale of 0 to 3 with 3 indicating more severe impairment. The DRS-R-98 is based on the DRS and developed to address shortcomings of the original scale. The DRS-R-98 assesses perceptual disturbances, hallucinations, delusions, motor agitation or retardation, orientation, attention, short-term and long-term memory, visuospatial ability, physical disorder, sleep-wake cycle disturbances, and affect. The diagnostic items include temporal onset of symptoms and fluctuation (Trzepacz, et al., 2001). The validation study of the DRS-R-98 compared this scale to the DRS, the Cognitive Test for Delirium, and the Clinical Global Impression scale (Trzepacz, et al., 2001). Five comparison groups were formed included persons with delirium, dementia, schizophrenia, depression, and others. These diagnoses were made using DSM-IV criteria and other available clinical data to support the diagnosis. The total number of participants in this study was 68, 24
of whom had delirium and 13 with dementia. The total sensitivity, differing based on comparison group, ranged from 85% to 100%, with a specificity of 77% to 100% (Trzepacz, et al., 2001). Based on this study, the DRS-R-98 is considered a reliable and valid tool in delirium symptom rating.

The CAC is a 25-item nursing checklist of psychomotor associated with confusion (Vermeersch, 1990). The scale ranges in score from 0 to 77, with higher scores indicating more confusion. The scale was developed based on 228 nurse ratings of 141 behaviors found in the literature to be associated with confusion in hospitalized adults (Vermeersch, 1990). The scale measures five general areas: cognition, behavior, motor activity, speech, orientation, and psychotic/neurotic behaviors, with some symptoms being weighted more than others. The CAC was validated compared to a visual analog scale of confusion. There was no description of persons involved in the validation studies.

The DOSS is a scale developed to help nurses recognize delirium early during routine care (Schuurmans, Donders, Shortridge-Bagget, & Duursma, 2002; Schuurmans, Shortridge Baggett, & Duursma, 2003). The scale is based on DMS-IV criteria for delirium and initially included 25 items rated on a 5-point Likert scale. After initial development and testing, the scale was reduced to 13 items rating as either 0=never or 1=always, three items are reversed scored with always interpreted as ‘normal behavior’. The maximum score is 13, with a cut-off score for delirium as 3. Items on the scale include assessing if the patient dozes during conversation or whether the patient is pulling at invasive devices, such as a catheter (Schuurmans, et al., 2002; Schuurmans, et al., 2003). The reliability and validity of the DOSS were tested in two prospective studies of hospitalized persons over the age of 70 years at high risk for delirium. The DOSS was compared to the CAM, MMSE, the IQCODE, and DMS-IV criteria for delirium. The DOSS is a reliable and valid tool of nurse detection of delirium in high-risk populations.

The NEECHAM Confusion Scale is a nine-item scaled tool further divided into three subscales developed to help nurses assess delirium in hospitalized older adults (Champagne, Neelon, McConnel, &
Funk, 1987). The NEECHAM score ranges from 0 to 39 points, with higher scores indicating higher functioning. A score between 0 and 24 indicates delirium. The first subscale assesses level of responsiveness and information processing with a score ranging from 0 to 14. This subscale evaluates orientation, memory, attention, and alertness. The second subscale uses general appearance and behaviors to rate level of behavior on a scale of 0 to 10, including posture, verbal responses, and sensory motor performance. The final subscale evaluates vital functions, such as pulse and urination, with a total score ranging from 0 to 16 points (Champagne, et al., 1987). The NEECHAM has been demonstrated to have high rates of reliability and validity in several populations (Neelon, Champagne, Carlson, & Funk, 1996; Neelon, Champagne, McConnel, Carlson, & Funk, 1992). A recent study (Gemert van & Schuurmans, 2007) compared the DOSS to the NEECHAM. Although both scales were determined to be reliable and valid, nurses preferred the DOSS because the information was more clinically relevant to the participants.

**Summary:** Formal healthcare provider tools for detection and recognition of delirium in persons with dementia. Results from studies looking at validation of several instruments demonstrate the wide range of tools available to assess for and detect delirium in older adults in the acute care setting. Research investigating the validity and reliability of these tools to detect delirium frequently included a sample of persons with pre-existing dementia, but no tool was specifically developed to detect and recognize delirium in this vulnerable population. A recent systematic review of tools to detect delirium superimposed on dementia suggests use of the CAM and the Confusion Assessment Method- Intensive Care Unit (CAM-ICU) as the best diagnostic tools for DSD (Morandi et al., 2012; Wong, et al., 2010). It has not been determined which assessment tools, or components of tools are best able to identify delirium in persons with pre-existing dementia. Morandi et al. (2012) identify the need for additional research in this area.
Multidimensional Interventions Aimed at Improving Delirium Detection, Recognition, and Management in Persons with Dementia for Formal Healthcare Providers

Current management strategies are aimed at prevention as the main management strategy for delirium to prevent negative sequelae associated with delirium (O'Hanlon et al., 2013). Multidimensional interventions have been most effective in prevention of delirium, with modest effective in improved detection and management of delirium. The following section will present some multidimensional interventions for delirium based on previously identified management strategies for delirium. These interventions have included persons with and without pre-existing dementia.

Multidimensional interventions have focused on delirium management through mitigating predisposing and precipitating factors to the best extent possible. Inouye and colleagues (1999) developed a multicomponent strategy aimed at delirium prevention titled the ‘Hospital Elder Life Program’ (HELP). The intervention targeted known predisposing and precipitating factors of delirium including: cognitive impairment, sleep hygiene, immobility, vision and hearing impairment, and dehydration. Components of the intervention were implemented using a multidisciplinary team and volunteers, to increase the feasibility and cost-effectiveness of this intervention (Inouye, et al., 2000). In a clinical trial, with a prospective, matched cohort design, HELP was tested in 852 patients over the age of 70 years old with an intermediate risk of developing delirium during hospitalization. The Confusion Assessment Method (CAM), Mini-Mental Status Examination (MMSE), and digit span were used to evaluate cognitive functioning. Over 25% of the sample included persons with pre-existing dementia. HELP was effective in decreasing the incidence of and shortening the duration of delirium (S. K. Inouye, et al., 1999). This multidimensional intervention was most effective in terms of delirium prevention. HELP has also been implanted in smaller, community medical center settings, resulting in a 40% decreased delirium incidence and significant cost savings (Zaubler et al., 2013).
As identified by Khan et al. (2012) an additional effective management strategy for delirium is the use of pro-active geriatric consultation. The concept of geriatric consultation may include cognitive screening and assessment, with recommendations for care such as nutrition and hydration, cognitive and physical stimulation, and medication management (E. Marcantonio, et al., 2001). Ideally all transdisciplinary team members are included within geriatric consultation, including informal caregivers. Marcantonio (2001) tested the use of consultation in a prospective, randomized controlled trial. All participants in this study were admitted to an acute care facility for a diagnosis of hip fracture. A total of 126 participants over the age of 65 years were enrolled. Thirty-seven percent of participants in the intervention group and 51% in the control group had a diagnosis of dementia. The intervention was found to be effective to reduce the incidence of delirium in persons without pre-existing dementia, but was not effective in persons with pre-existing dementia. It was believed that the precipitating event of delirium occurrence was the acute illness and subsequent transition to the acute care setting (E. R. Marcantonio, et al., 2001). It may also be increasingly difficult to prevent delirium in persons with pre-existing dementia. A significant limitation of geriatric consultation is the assumption that all recommendations from the transdisciplinary care team were implemented and enacted appropriately. This is a major assumption and difficult to measure.

Using registered nurses, and other nursing staff, has been identified as a mechanism to improve detection, recognition, and management of delirium in persons with and without dementia due to the presence of nursing staff at the bedside (Greer, et al., 2011; O’Hanlon, et al., 2013). Nurse focused interventions have been tested across settings of care. Milisen et al. (2001) assessed the effectiveness of a nursing based intervention on delirium incidence, duration, and severity of delirium in acute care patients admitted for a diagnosis of hip fracture (Milisen, et al., 2001). Long-term outcomes, measured at three months, were also examined, including physical and cognitive function and acute care readmission. The intervention included nurse education regarding dementia, delirium, and depression,
operationalized as a poster on the unit. Systematic assessment of delirium risk was done and for patients at high risk for delirium a geriatric resource nurse was consulted. The final piece of this intervention was administration of routine pain medication (Milisen, et al., 2001). A total of 120 older adults were enrolled with equal distribution in the intervention and control groups. Twelve individuals in the intervention group developed delirium and 14 in the control group; the difference was not statistically significant (Milisen, et al., 2001). There was also no statistically significant difference in terms of length of stay, functional ability, or mortality; however, persons in the intervention group had a significantly shorter duration of delirium. Persons with delirium also had functional decline at one and three months after acute care hospitalization, indicating lasting delirium effects (Milisen, et al., 2001).

Summary: Multidimensional interventions aimed at improving delirium detection, recognition, and management in persons with dementia for formal healthcare providers.

Multidimensional interventions aimed at delirium detection, recognition, and management has focused on mitigating predisposing and precipitating factors, geriatric consultation, and nurse-focused interventions. This is not an exhaustive list, but provides a broad understanding of several multidimensional interventions in this area. The majority of this research has included persons with pre-existing dementia, but there is a limited amount of research focused on this vulnerable population in the acute care setting. Despite continued focus on research and practice regarding delirium, it continues to be a widespread problem leading to adverse outcomes in persons with pre-existing dementia. Informal caregivers are a potential mechanism to improve delirium detection, recognition, and management in this population and setting.

Improving Recognition and Detection of Delirium in Persons with Dementia through the Use of Informal Caregivers
Informal caregivers have been used in delirium detection, recognition, and management in populations other than persons with pre-existing dementia. Persons with cancer, particularly at the advanced stages, frequently experience delirium (Cohen, Pace, Kaur, & Bruera, 2009). Common causes of delirium in this population are similar to causes of delirium in persons with dementia and include medications, infection, and fluid and electrolyte imbalance (Bruera, et al., 2009). The impact of delirium on informal caregivers will be presented to understand the significance on this population. In addition, patient and informal caregiver characteristics impacting detection, recognition, and management will be discussed. Lastly, multidimensional interventions involving informal caregivers and delirium across settings of care will be emphasized.

**Impact of Delirium on Informal Caregivers**

The effects of delirium on formal healthcare providers and the larger healthcare system have been described previously in this review. Delirium also has significant emotional and physical impact on informal caregivers, as well as the individual.

Breitbart and colleagues (2002) sought to examine the prevalence and the level of distress associated with delirium in patients and informal caregivers with cancer in the acute care setting. This prospective, observational study enrolled 101 patients, ranging in age from 19 to 89 years, and 75 informal caregivers. Almost 20% of the sample had a pre-existing diagnosis of dementia. All had experienced delirium during the acute hospitalization (Breitbart, et al., 2002). Over 53% of the patients recalled the delirium episode; recall decreased with age. Almost 1/3 (28%) of patients with pre-existing dementia recalled the delirium episode. Eighty percent of informal caregivers, and 73% of formal healthcare providers, experienced distress in this study related to the delirium episode (Breitbart, et al., 2002). Delirium was demonstrated in this study to be a distressing event across groups, indicating an increased need for prompt detection, recognition, and management.
Bruera and colleagues (2009) also sought to understand the prevalence of delirium recall in cancer patients, and the level of distress associated with delirium in patients, informal caregivers, and formal healthcare providers. Ninety-nine patient and informal caregiver dyads participated in this study. Patients were over the age of 18 years, with an average age of 60 years. Informal caregivers in this study were defined as a spouse, adult child, sibling, parent, relative or significant other present at the bedside for at least 2 hours each day during the delirium episode (Bruera, et al., 2009). The average age of informal caregivers was 55 years (Bruera, et al., 2009). A total of 74% of patients recall being confused, with those experience hyperactive delirium statistically more likely to recall the episode. Informal caregivers recalled more delirium symptoms than patients or formal healthcare providers and experienced severe distress. Results indicate informal caregivers are able to detect and recognize delirium symptoms.

A study by Clissett, Porock, Harwood, & Gladman (2013) conducted semi-structured, qualitative interviews with 34 informal caregivers of adults over the age of 70 years admitted to acute care with pre-existing cognitive impairment, defined as dementia or delirium. Information on patient and informal caregiver demographics was not given, nor was prevalence of delirium superimposed on dementia. Informal caregivers in this study noted a disruption in normal as a qualitative theme (Clissett, et al., 2013). Informal caregivers in this study dealt with distress associated with dementia and delirium by attempting to be involved in care of the hospitalized older adult.

A similar study was done by Toye et al. (2013). Using mixed methods, including a semi-structured qualitative interview, Toye et al. (2013) examined the impact of delirium on patients and informal caregivers in the acute care setting, as well as describe their delirium knowledge and care needs. A total of 17 informal caregivers and 11 persons with delirium participated in the study, three of which had pre-existing dementia. Informal caregivers stated that they experienced distress and wanted
more education regarding delirium, delirium management, and how informal caregivers can add to care of the patient (Toye, et al., 2013).

In summary, the results from this research demonstrate the significant impact of delirium on informal caregivers. Although these studies involve persons with cancer and their informal caregivers, the results can be transferred to persons with dementia and their caregivers. The impact of delirium is felt on an individual level, across care providers, and at a larger systemic level (Partridge, Martin, Harari, & Dhesi, 2012).

**Factors Impacting Recognition and Detection of Delirium in Persons with Dementia by Informal Caregivers**

Given that patient and healthcare provider factors impact detection, recognition, and management of delirium by formal healthcare providers, it can be assumed that there are potential factors influencing informal caregivers. Patient factors were taken from those impacting formal healthcare providers. In addition, several disease or condition symptoms have also been associated with improved recognition of illness, including severity of illness and type of symptoms. Considering the overlap between dementia and delirium, potential factors that have been identified in the literature as impacting recognition of dementia by informal caregivers may also impacting recognition of delirium. Although there is a lack of information regarding informal caregiver recognition of symptoms associated with delirium in hospitalized older adults with dementia, there are several characteristics of caregivers associated with recognition of dementia and other conditions (Bond, 2009). Patient factors will be presented first.

**Patient factors.** A potential factor associated with recognition of illness is disease severity (Zanetti, et al., 1999). Eustace and colleagues (2007) sought to identify factors associated with recognition of dementia by informal caregivers of community dwelling older adults meeting ICD-10
criteria for dementia. Proposed variables associated with recognition of dementia included functional status assessed using the Blessed Dementia Rating Scale (Blessed, Tomlinson, & Roth, 1968), disease severity assessed using the Clinical Dementia Rating Scale (Hughes, Berg, Danziger, Coben, & Martin, 1982), and behavioral disturbance using the Dementia Behavior Disturbance Scale (Baumgarten, Becker, & Gauthier, 1990). Behavioral disturbances include symptoms of dementia such as repetitive questioning, lack of interest in daily activities, losing or hiding things, being awake at nighttime, experiencing excessive daytime sleepiness, and pacing (Baumgarten, et al., 1990). Psychiatric symptoms of dementia were assessed using the Behavioural Pathology in Alzheimer’s Disease Rating Scale (BEHAVE-AD) (Reisberg, Borenstein, Salob, & Ferris, 1987). Sociodemographic data was collected about the patient, but not about the informal caregiver. A total of 62 participants and their caregivers were included in the results. Behavioral disturbance was significantly correlated with recognition of symptoms of dementia in this study, while functional impairment was not significantly related to recognition of dementia.

This study is important to understanding informal caregiver recognition of symptoms of delirium. Hypoactive delirium is commonly undetected by formal healthcare providers (Fick, Hodo, et al., 2007; Fong, Tulebaev, et al., 2009; Mittal, et al., 2011). Persons with hypoactive delirium experience less behavioral disturbance and may be less likely to be recognized as having delirium by informal caregivers as well. In addition, there are several overlapping features between dementia and delirium. Persons with severe dementia frequently experience more behavioral disturbances than those with mild or moderate dementia (MacDonald, et al., 2011; Tschanz, et al., 2011). The overlap in features between dementia and delirium may lead to a misappropriation of symptoms of delirium to those of dementia, particularly in persons with a severe underlying dementia.

**Informal caregiver factors.** A characteristic of the informal caregiver that may impact recognition of symptoms of delirium was extracted from the literature surrounding persons with
dementia and additional illnesses or conditions as described. Characteristics include the type relationship between the hospitalized older adult and the informal caregiver, living arrangement outside of the acute care setting, prior educational level, race, and previous knowledge or experience with delirium.

**Relationship.** Type of relationship, including spousal or parent/child may impact the recognition of delirium symptoms. These types of relationships also account for gender differences in the recognition of subtle mental status changes as seen in recognizing slight symptoms of Alzheimer’s and related disorders and disclosing cancer diagnoses (Hayes, et al., 2010; Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009).

Gender is an important consideration in the recognition of symptoms, particularly gender roles within a marital relationship. Hayes et al. (2010) recently explored the impact of gender on spousal awareness and reaction to subtle changes associated with Alzheimer’s disease. They identified patterns of awareness, help-seeking, and communication between the couple regarding symptoms through intensive, qualitative interviews with informal spousal caregivers of individuals with Alzheimer’s disease and other related disorders. The final sample included 28 caregivers, 13 men and 15 women, who had been providing care for their spouse for at least six months. Their findings reveal that women often recognize subtle changes in memory, behavior, and mood that were the beginning symptoms of Alzheimer’s disease (Hayes, et al., 2010). In addition, the male spouses revealed that daughters, daughter-in-laws, and other female family members frequently alerted them to changes before they noticed these changes. Interestingly, once noticing changes males were more open discussing the meaning of these changes and seeking professional medical advice, while females were hesitant to take action and talk with their spouses about their concerns (Hayes, et al., 2010). This study suggests an important gender difference. Females, whether or not in a spousal relationship, may be quicker to
notice symptoms, yet less likely to report these symptoms to a professional healthcare provider, such as a nurse or physician.

**Living arrangement.** Living arrangement between the informal caregiver and hospitalized older adult with dementia is a potential predictor in the recognition of delirium in hospitalized older adults with dementia. McLoughlin et al. (1996) sought to compare the cognitive ratings of informal caregivers of community-dwelling persons with dementia to objective, standardized cognitive testing and assessment. Informal caregivers characteristics measured relationship and frequency of contact (McLoughlin, et al., 1996). A total of 170 persons with dementia and their informal caregiver were enrolled in this study through a registry of community dwelling persons with dementia. The caregivers completed the CAMDEX interview and the Blessed Dementia Rating Scale (BDRS). Persons with dementia were objectively assessed using the Mini-Mental Status Examination (MMSE), Abbreviated Mental Test Score (AMTS), and through other tests assessing praxis and visual agnosia (McLoughlin, et al., 1996). This study demonstrated that informal caregivers were good informants in the severity of cognitive impairment and illness. Informal caregivers living with the person with dementia were more likely to appropriately rate the level of impairment and recognize the changes associated with memory and orientation. All but one of the informal caregivers living with the older adult with dementia was a spouse. This study suggests that informal caregivers, who have frequent contact with older adults with dementia, may be able to more accurately detect subtle mental status changes associated with delirium in hospitalized older adults with dementia.

**Informal caregiver education level.** Rovner and colleagues (2011) determined that educational level impacted the response of informal caregivers to changes in thinking and memory in community-dwelling older adults. This study sought to explore racial differences in informal caregiver ratings of cognitive status in 252 community-dwelling older adults receiving home care services through senior health agencies (Rovner, et al., 2011). Informal caregivers were interviewed in-person or over the
telephone using the Informant Questionnaire for Cognitive Decline in the Elderly (IQCODE). They were also asked about their demographic background, relationship to the older adult, and the participants' family history with dementia, medical history, cognitive function, possible start of cognitive decline, and need for assistance with ADLs and IADLs. An expert consensus panel made diagnoses in the community dwelling older adults of normal cognition, cognitive impairment no dementia, and dementia based on standardized neuropsychiatric testing and evaluation conducted in the participants' home. A total of 161 of the participants were white, and 86 were black. The main findings from this study suggest that informal caregivers with lower educational levels are less likely to rate their loved one as experiencing cognitive decline as measured by the IQCODE (Rovner, et al., 2011).

**Informal caregiver knowledge and experience.** Familiarity with an illness or disease is associated with a greater likelihood of symptom recognition (Galvin, Fu, Nguyen, Glasheen, & Scharff, 2008; Ross et al., 1997; Werner, 2003, 2004). Werner (2003) conducted a study to understand the relationship between knowledge of symptoms of Alzheimer’s disease (AD) and health seeking behavior in community-dwelling persons over the age of 45 years. Participants with a close relative with AD were purposefully excluded. Werner also sought to understand correlates to knowledge about AD, including education and income levels and prior experience with AD. Knowledge regarding AD symptoms was assessed using a researcher-developed Likert-type scale (Werner, 2003). Participants were the likelihood of seeking professional care for any of the symptoms presented on the tool. Overall results from this study demonstrate that most people have some knowledge about the symptoms of AD. Over 60% of participants were able to correctly identify warning signs of AD related to language disturbance, orientation, difficulty conducting usual and familiar tasks, decreased judgment, difficult performing abstract problem solving, loss of initiative, and changes in overall mood or behavior. Werner found that prior experience with AD was significantly associated with improved symptom recognition. This suggests that individuals who have prior knowledge of an illness or condition may be more likely to identify
symptoms. Several studies have found similar results in persons seeking help for symptoms of a myocardial infarction (MI) or an acute stroke (Cytryn, et al., 2009; Hsia, et al., 2011; Ratner, et al., 2006; Zerwic, et al., 2007).

**Summary: Potential Factors Impacting Recognition of Delirium**

Although there is a lack of knowledge regarding potential factors that may impact or influence informal caregiver recognition of delirium in hospitalized older adults with pre-existing dementia, there are several studies which suggest potential factors found to be influential in other populations. Characteristics of informal caregivers that may influence recognition of delirium include their relationship to the person with dementia, living arrangement, prior experience or knowledge of delirium, and educational level. In addition, characteristics of the illness, including severity of delirium and underlying dementia, may impact symptom recognition. These characteristics are important to understand which informal caregivers may need additional education or information related to the importance of early recognition of delirium during an acute care hospitalization.

**Tools for Informal Caregiver Recognition and Detection of Delirium in Persons with Dementia**

To date one tool has been used to assess for informal caregiver detection of delirium in persons with pre-existing dementia, the Family Confusion Assessment Method (FAM-CAM) (Steis, Evans, et al., 2012). Evidence suggests that the Confusion Assessment Method is the most valid and reliable tool for formal healthcare provider detection of delirium in persons with dementia (Morandi, et al., 2012). This was determined based on prior research comparing CAM ratings of delirium to an identified gold standard. The FAM-CAM builds upon the CAM and also incorporates informal caregiver detection of the following delirium symptoms: disorientation, perceptual disturbances, and inappropriate behavior (Steis, Evans, et al., 2012). The tool is meant to be a screening tool for delirium using informal caregiver observation. Steis et al. (2012) conducted an exploratory of 52 paired researcher and informal caregiver ratings of delirium using the CAM and FAM-CAM, respectively. This study was done within the home
healthcare context and all patients had a baseline of pre-existing dementia. Agreement between the two ratings was excellent in this convergent validity study (Kappa=0.85) (Steis, Evans, et al., 2012).

**Interventions Improving Informal Caregiver Recognition and Detection of Delirium Across Populations**

Informal caregivers of persons with delirium and delirium superimposed on dementia in multiple settings and may be able to recognize acute cognitive changes associated with delirium more quickly than formal healthcare providers (Bond, 2009). Informal caregivers are important members of the transdisciplinary healthcare team (Coleman, 2011; Li, et al., 2003). They become even more critical in vulnerable populations, such as persons with pre-existing dementia, where delirium is more common, associated with increased sequelae, and costly.

Delirium recognition, prevention, and management intervention involving informal caregivers of older adults in multiple contexts and across settings will also be summarized as a way to understand the current scientific literature that forms a foundation for the proposed study. To date the majority of informal caregiver focused interventions have been conducted in persons with advanced cancer. Those highlighted here include the following main delirium recognition, prevention, and management strategies: increasing communication, educational enhancement strategies, multidimensional interventions, geriatric consultation, and transitional care. Examples will be provided to support these types of interventions.

An informal caregiver-focused intervention, Creating Avenues of Relative Empowerment (CARE), was pilot tested in a randomized clinical trial (Li, et al., 2003). The intervention aimed at improving communication between informal caregivers and formal healthcare providers. The intervention was not specific to delirium, but the goal was to prevent common adverse events associated with acute care hospitalization for older adults, including delirium. Patients with dementia were purposefully excluded from participation. The intervention consisted of two components: 1) an educational piece for informal
caregivers on what to expect during hospitalization and 2) a mutual agreement contract between the informal caregiver and formal healthcare providers (Li, et al., 2003). Intervention follow-up was conducted at 2 weeks and 2 months, with data collected from both informal and formal healthcare providers, mainly nurses. Results included lowered rates of depression, incontinence, readmission at 2 months, and a patient confusion. Overall informal caregivers in the intervention group spent significantly more time caring for their family member, according to both informal caregiver and nurse report. Informal caregiver coping was also reported to be improved in the intervention group (Li, et al., 2003).

A primary delirium prevention intervention was designed by Black et al. (2011) to be implemented upon hospital admission. Informal caregivers were considered critical to implementation of a prevention program in the care of critically ill adults. A comparative time-series study was conducted using an intervention (n=87) and control group (n=83), patient age ranged from 18-78 years (P. Black, et al., 2011). The intervention consisted of an education booklet provided to informal caregivers regarding potential stressors during critical illness, including delirium, and personalized management techniques. Although informal caregivers perceived the intervention to have a positive impact on overall well being, there was no statistically significant difference in rates of incident delirium across the two groups. Results from partnering with informal caregivers are mixed.

Increased education has been touted as a mechanism to improve informal caregiver detection, recognition, and management of delirium (Gagnon, et al., 2002; Otani et al., 2013). This is similar to research studies aimed at formal healthcare providers. Establishing a baseline of current knowledge is needed, as well as providing additional training. A multi-phase study was conducted to first develop a psycho-educational framework and intervention for informal caregivers of persons with advanced cancer and secondly to implement the intervention, with assessment of impact and outcomes (Gagnon, et al., 2002). Holding focus groups with informal caregivers and initial pilot testing developed an
educational brochure. The brochure included recommendations such as promotion of frequent and direct communication between informal and formal caregivers. A total of 66 family caregivers were included in the final phase intervention group, with 58 in the control group. Results demonstrated that delirium is a significant concern for informal caregivers of persons with advanced cancer. After the intervention, families reported being more attentive and spending more time with the patient to observe for delirium symptoms and it improved their confidence in dealing with delirium (Gagnon, et al., 2002).

Otani et al. (2013) conducted an educational intervention as well. Using a historical, case-controlled method, they compared delirium education received via in-person communication to an educational brochure across four palliative care units and three care homes in Japan. Data was collected from 113 informal caregivers after the death of their family member using a researcher-developed questionnaire on their delirium experience. Results from this study indicate that informal caregivers who received the educational brochure versus in-person education routine education felt better prepared to deal with the delirium experience and that it improved their knowledge.

In addition to education and knowledge-focused interventions, multidimensional interventions have tailored delirium interventions for use in a specific population or setting. Benedict et al. (2009) conducted a feasibility study of an intervention designed to prevent, detect, and intervene in the course of delirium in high risk hospitalized patients over the age of 60 years. The intervention was implemented on an acute care for the elderly (ACE) unit, while a similar unit served as the control. Participants were community dwelling older adults with a mean age of 78 years, and had a score of at least 5 on the Short Portable Mental Status Questionnaire (SPMSQ) (Benedict, et al., 2009). The multicomponent intervention was a compilation of strategies identified in the literature including nursing education, routine mental status assessment, and enhanced interdisciplinary communication. Informal caregivers
were encouraged to be present at the bedside and an educational booklet that listed strategies to help informal caregivers prevent delirium and ways to help with activities of daily living. Thirteen of the 70 patients in this study had delirium, with nine in the intervention group. Overall, the intervention did not have a significant effect on the incidence of delirium between the two groups (Benedict, et al., 2009). The authors report an adherence rate of 100% to the intervention. This study has significant limitations. First it is a feasibility study and it not sufficiently powered to detect a larger difference. Secondly, it is difficult to measure the impact of each intervention component. There were also more patients in the treatment group. The last major limitation is the lack of reporting of informal caregiver involvement in the care of the hospitalized elder.

Using the Hospital Elder Life Program (HELP) (Inouye, et al., 2000) as a model, Gagnon et al. (2010) tested a multicomponent intervention included a delirium risk assessment, conducted by the physician and an educational element for family caregivers provided by nursing staff to evaluate impact on delirium incidence (Gagnon, et al., 2010). The population of interest was individuals with end-stage cancer admitted to a palliative care unit. Informal caregivers were identified and provided education on delirium symptoms and prevention strategies (Gagnon, et al., 2010). A total of 1,516 patients admitted to one of seven palliative care centers participated in this three-year study; 674 patients were in the intervention group. Compared to usual care, the intervention did not demonstrate reduced delirium incidence, severity, or duration and did not extend delirium-free survival time among inpatients receiving terminal cancer care (Gagnon, et al., 2010). A significant limitation of this study was the brevity of the family caregiver education component of the intervention. This piece was purposefully kept short to avoid unnecessary caregiver burden, but may have been too brief to be effective in preventing delirium.
An additional multi-component intervention was based on the HELP principles, but modified to be integrated into daily practice to prevent delirium (Vidán, et al., 2009). Using a prospective, controlled clinical trial Vidan and colleagues (2009) compared elders over the age of 70 years and at risk for delirium, as identified by having cognitive or visual impairment, dehydration, and/or acute illness, in either a geriatric unit (n=170) to two general medicine units (n=372). The intervention consisted of two main components: a staff educational program and a set of actions aimed at reduced risk of delirium (i.e. maintain nutrition and hydration). Also included in the intervention was a letter to informal caregivers outlining the intervention and encouraging their presence at the bedside (Vidán, et al., 2009). Although no data was presented regarding the involvement of family in the care of these elders, the intervention was effective in reducing the incidence of delirium, but had no effect once delirium occurred.

A third intervention based on HELP principles was pilot-tested for feasibility. This intervention, titled Family-HELP, was meant as an adjuvant to HELP programs within an acute care system and involved informal caregivers in several HELP protocols (Rosenbloom-Brunton, et al., 2010b). A descriptive, exploratory study involving 15 family caregivers and 15 hospitalized older adults over the age of 65 years with at least one risk factor of delirium. The Family-HELP intervention focused on involving informal caregivers in vision and hearing management, orientation and therapeutic activity protocols, and early mobilization activities as embedded within the original HELP protocols (Inouye, et al., 2000). Family members were trained by the research team to participate in the intervention protocols and also completed a daily log outlining time spent on each activity, and reasons why they did not complete the activity if that was the case. In addition, information was collected from the nursing staff regarding family involvement in the intervention. No patients in this study developed delirium from baseline until discharge. Informal caregivers reviewed the intervention positively, and nursing staff reported increased communication and involvement of family caregivers in the care of the hospitalized
older adults (Rosenbloom-Brunton, et al., 2010b). Results must be interpreted with caution. This was a feasibility study, with no comparisons groups. More work is needed in this area.

Systematic detection and management of delirium in hospitalized older adults was tested in a randomized clinical trial on the effectiveness of resolving delirium and improving cognitive functioning in hospitalized older adults (Cole, et al., 2002). The intervention consisted of two main components. The first was geriatric consultation, which considered the predisposing, precipitating, and continuing factors associated with delirium in the hospitalized individual. In addition, recommendations for care were made to the primary care physician. The second element of the intervention was a study nurse who conducted daily mental status assessment on the hospitalized elder, and worked with informal caregivers and nursing staff to promote their involvement in care. A total of 227 individuals participated in the trial with 113 in the intervention group, and 114 receiving usual care (Cole, et al., 2002). Approximately one-third of the participants had underlying dementia. The intervention was not statistically significant in delirium resolution in persons with pre-existing dementia. Family involvement in care was not measured or reported in this study, but was merely encouraged by the study nurse.

A multidisciplinary team developed the Quality Cost Model of Advance Practice Nurse (APN) Transitional Care, also referred to as the APN Care Model or the Transitional Care Model (Naylor & Sochalski, 2010), to improve the quality of health care across sites, decrease readmissions and overall healthcare costs (Naylor et al., 1999; Naylor et al., 2004; Naylor et al., 1994). The model includes a series of home visits, telephone availability of an APN for questions, and physician support. The APN initially makes contact with the hospitalized individual, and the informal caregiver in the acute care setting. Goals and educational needs of this vulnerable dyad are identified during this time. After discharge the APN makes a series of home visits and telephone calls to the patient and their informal caregiver based on identified needs. Physical, emotional, and functional status of the patient is monitored by the APN in addition to providing direct care. Naylor and colleagues conducted an exploratory study to identify the
needs of older adults with dementia, delirium, or both, and their family caregivers during the transition from hospital to home (Naylor, Stephens, Bowles, & Bixby, 2005). Findings from this study suggest that patients and family caregivers continue to have many unmet educational needs during the transition from hospital to home. Currently the APN Care Model is being tested in older adults with cognitive impairment, including dementia and delirium (Naylor et al., 2007; Naylor, et al., 2005).

**Summary: Interventions improving informal caregiver recognition and detection of delirium across populations.** In summary, several multicomponent and educational interventions have been shown to be effective in increasing informal caregiver recognition and management of delirium and its associated symptoms in hospitalized older adults with and without dementia. Informal caregivers have been involved in delirium recognition and prevention within the context of several illnesses including advanced cancer and in hospitalized older adults at high risk for delirium. These multicomponent interventions have included staff education, routine delirium screening, geriatric consultation, and informal caregiver education. Few interventions partnered informal caregivers with nurses, only one has focused on persons with underlying dementia, and no known interventions have focused on enhancing communication between informal caregivers and healthcare professionals. There is a lack of information regarding the communication between informal caregivers and professional healthcare staff regarding recognition of symptoms of delirium in hospitalized older adults.

**Summary: Improving Recognition and Detection of Delirium in Persons with Dementia through the Use of Informal Caregivers**

Delirium is a distressing event for informal caregivers of persons with and without dementia in the acute care setting and beyond. To date one tool has been tested comparing informal caregiver ratings of delirium symptoms to trained researcher ratings. Patient and informal caregiver characteristics impact detection, recognition, and management of delirium, which have been taken from
related research. Multidimensional work has been done, but mainly with delirium in persons with end-stage cancer.

**Summary: Chapter 2**

Delirium is a significant problem for hospitalized older adults, particularly those with pre-existing dementia. Older adults who experience delirium while in the acute care setting are more likely to experience adverse events, such as decreased cognitive and physical functioning, higher rates of institutionalization after discharge, and an increased rate of mortality (Bellelli, et al., 2007; Covinsky et al., 2003; Fick, et al., 2002; Inouye, 2006a). Despite the large burden of delirium, it is frequently under recognized in hospitalized older adults. In persons experiencing hypoactive delirium or delirium superimposed on dementia, it is less likely to be documented. Several multicomponent interventions have involved formal and informal healthcare providers to improve prevention, recognition, and management of delirium in hospitalized persons; however, none of this research focuses purely on hospitalized older adults with dementia. The proposed study will address this significant gap in the literature by exploring informal caregiver recognition and reporting of symptoms of delirium in hospitalized older adults with pre-existing dementia.
Chapter 3

Methods

This descriptive, exploratory study investigates informal caregiver detection and recognition of symptoms of delirium in older adults with pre-existing dementia; identifying patient and informal caregiver characteristics related to reporting of delirium symptoms by the informal caregiver; and describes the hospital experience for informal caregivers of persons with pre-existing dementia and delirium.

Study Design

This descriptive, exploratory study utilized participants concurrently enrolled in a National Institute of Nursing Research Study Early Nurse Detection of Delirium Superimposed on Dementia (END-DSD) (5R01NR011042-02) to illustrate detection and recognition of symptoms of delirium by family caregivers of persons with an underlying dementia. The purpose of the parent study, END-DSD, is to test a multi-component intervention strategy aimed at improving nurse recognition and management of delirium in hospitalized persons over the age of 65 years with dementia. Participants enrolled in END-DSD include hospitalized older adults with a baseline of dementia and their informal caregivers. Several measures currently being collected in the parent study will be utilized in this study. The control group from the parent study will be targeted to avoid any bias regarding increased involvement and communication between informal caregivers and formal healthcare providers in the intervention group of the parent study. All patient measures in the proposed study are extracted from the larger parent study. In addition, this study also collected exploratory data from informal caregivers in a post-hospitalized telephone interview not conducted as a component of the parent study. The specific aims of this study will be addressed in the following manner.
Specific Aim 1: To compare the agreement between informal caregiver assessment of delirium, the Family Confusion Assessment Method (FAM-CAM) to trained research assistant (RA) assessment of delirium using the Confusion Assessment Method (CAM) in hospitalized older adults with underlying dementia.

To meet the objectives of this specific aim, informal caregivers will be assessed for their detection and recognition of symptoms of delirium according to the Family Confusion Assessment Method (FAM-CAM). The FAM-CAM will be administered to an informal caregiver within 48 hours of acute care admission for the person with dementia. This tool objectively measures the detection and recognition of symptoms of delirium up to one week prior to hospital admission. In addition, informal caregivers will also be within 7 days after discharge of the person with dementia regarding their detection and recognition of delirium symptoms during the acute care hospitalization.

Specific Aim 2: To evaluate factors associated with reporting of symptoms of delirium by informal caregivers, including: dementia stage; delirium severity; delirium motoric subtype; relationship between the informal caregiver and care recipient; living arrangement between the informal care caregiver and care recipient; education level of the informal caregiver; and pre-existing knowledge of or experience with delirium.

A trained research assistant, using the Delirium Rating Scale-Revised-98 (DRS-R-98), will measure delirium severity within 48 hours of hospital admission of the care recipient. Motoric subtype of delirium will be identified and will serve as a possible correlational factor to the recognition of delirium. Subtypes of delirium include hyperactive, hypoactive, and mixed delirium. Motoric subtype will be evaluated by the DRS-R-98 within 48 hours of hospital admission.

Additional informal caregiver variables known to contribution to symptom recognition will also be measured: caregiver level of education, and living arrangement (i.e. whether the caregiver and care
recipient living together). Both of these characteristics will be assessed in a post-discharge telephone interview conducted within 7 days of discharge (See Appendix A).

**Specific Aim 3**: To describe the hospital experience, and the detection and recognition of symptoms of delirium, from the perspective of informal caregivers of persons with pre-existing dementia.

The objectives of this specific aim will be addressed in three ways. First, informal caregivers will be asked to describe the thinking and memory of the patient with pre-existing dementia during the course of the hospitalization and how they have been doing since hospital discharge. Also, during the telephone call, informal caregivers will be asked if they reported any symptoms or changes in thinking and memory that they noticed to a professional healthcare provider, including, but not limited to the following:

- Physician, Physician Assistant, or Nurse Practitioner
- Registered Nurse or Licensed Practical Nurse
- Certified Nursing Assistant, Nursing Assistant, or Nurse Aide
- Social Worker or Case Manager
- Other

In addition to being asked if they reported these symptoms, informal caregivers will also be asked if any formal healthcare provider asked them about symptoms they may have noticed or about the thinking and memory of the hospitalized older adult. The final piece of communication that will be evaluated will include any education or discharge teaching related to changes in thinking or memory that they may have received during the hospital period. In the post-discharge interview, informal caregivers will be asked if they received any information during discharge teaching or education regarding delirium symptoms or prevention from any formal healthcare provider (See Appendix A).
Setting

This will be a two-site study conducted within two acute care hospitals in Pennsylvania. Over a twelve to eighteen month period, it is expected that informal caregivers will be enrolled from each of the sites.

Expected and Actual Enrollment

Enrollment is based on meeting the objectives of the parent study, END-DSD. Expected monthly enrollment in the parent study is nine hospitalized older adults with pre-existing dementia and their informal caregivers. Dyads are recruited from two sites within the parent study, both located in central Pennsylvania. END-DSD is a cluster-randomized, controlled clinical trial. There are two units from each of the three sites within the parent study, one unit allocated as intervention and the other as control. As of April 30, 2013 a total of 317 patient and informal caregiver dyads were enrolled in the parent study across all three sites. As of April 30, 2013 a total of 145 dyads were enrolled at one of the central Pennsylvania sites, with 43 allocated to the control group. For the same time period, a total of 80 dyads were enrolled at the other site, with 39 allocated to control. Participants for this study were drawn from these dyads.

Study Sites

The first study site is a community medical center located in Centre County in central Pennsylvania. It is a 200 bed acute care hospital with three medical-surgical units and two intensive care units; providing cardio-thoracic, orthopedic, and neurosurgery services to residents in the surrounding community. During the period of January 1, 2010 through December 31, 2010 this site had a total of 12,866-inpatient admission, with 4,081 of those admissions being persons over the age of 65 years. This study will take place on a medical-surgical-orthopedic unit.
The second site is also located in Central Pennsylvania, in Blair County. It is a 500-bed regional, acute care facility with three medical-surgical units and four critical care units. During the 2007 calendar year, the facility had a total of 7,342 inpatient admissions of persons over the age of 65 years, which represents over 43% of their total inpatients admissions. This study will take place on a general medical unit within this facility.

Sample

Potential subjects will include hospitalized older adults, their informal caregivers, and the formal healthcare providers caring for these individuals. The inclusion and exclusion criteria listed below are those in the parent study, END-DSD. Within 48 hours of hospital admission, potential participants are screened for the following inclusion criteria: English speaking, 65 years or older, admitted to the selected hospital unit, and meet criteria for dementia (Pisani, Inouye, McNicoll, & Redlich, 2003). Screening for dementia is done using informal caregiver rating based on the Modified Blessed Dementia Rating Scale. For the purpose of this study, dementia will be defined as having a duration of symptoms of at least six months and a score of greater than three on the Modified Blessed Dementia Rating Scale (MBDRS) (Blessed, et al., 1968); additional data may be collected from the primary healthcare provider, other caregivers, and through chart review as needed to determine if the patient had an underlying dementia. A score of greater than two on the MBDRS has been used to indicate possible dementia (S. K. Inouye, et al., 1999), but a more conservative measure of greater than three will be used for enrollment in this study. This method, using proxy measured MBDRS and chart review, has been validated to determine the presence of dementia using DSM-III-R criteria (Froehlich, Robison, & Inouye, 1998; S. K. Inouye, et al., 1999).

Exclusion criteria include: having any significant neurological or neurosurgical disease associated with cognitive impairment other than dementia, such as Parkinson’s disease with dementia,
Huntington’s disease, normal pressure hydrocephalus, seizure disorder, subdural hematoma, head trauma, or known structural brain abnormalities; are nonverbal and unable to communicate, have aphasia, intubation or terminal illness; have a life expectancy of 6 months or less; have severe psychiatric disease or acute depression; or have no family or caregiver to interview. Persons with pre-existing delirium will not be excluded. Subjects are not excluded are the basis of race, gender, or ethnicity.

Potential subjects are screened at each facility, Monday through Friday, by a trained research assistant (RA) using hospital provided demographic information including age of potential subject, admission time and reason for admission, and primary contact name and telephone number. The RA approaches the patient’s nurse to determine if any exclusionary criteria are present. The hospitalized older adult is then approached for verbal consent to participate in the study. If permission is obtained, the RA then approaches the identified primary contact in person, if they are present, or via telephone.

Upon agreement from the informal caregiver, a proxy screen is administered to that individual to determine if he/she is the best person to assess the memory and mental abilities of the hospitalized older adult. This screening instrument, used within the larger END-DSD study, assesses whether the proxy and patient have known each other at least 5 years, see each other at least twice weekly, and spend a minimum of four hours together weekly. If the initial individual contact, as designated upon hospital admission, is not the best person to assess the cognitive status of the hospitalized person with dementia, another proxy is identified and then contacted to participate in the study. This protocol is outlined in the parent study. For the purpose of this study, only one informal caregiver will be approached since the proxy-screening tool is designed to identify the individual best suited to assess thinking and memory of the care recipient. Inclusion criteria for the informal caregiver are as follows:
English speaking; able to be contacted via the telephone for a post-discharge follow-up phone call; and agree to participate in this study.

Measures

Measures collected in this study include patient and informal caregiver baseline measure extracted from the larger parent study, as well as prospective data obtained to meet the purpose and aims of this study. All data except for the post-hospitalization telephone interview will be collected by RAs within the parent study and will be extracted from the END-DSD database for use. A copy of all instruments can be found in Appendix B.

Patient Measures

Patient measures include demographic characteristics, dementia stage, delirium presence, and delirium rating scale/severity measure, and delirium motoric subtype (Table 1). This data will be extracted from the larger, parent study END-DSD.

Dementia presence. Dementia will be defined as having a duration of symptoms of at least 6 months and a score of greater than 3 on the Modified Blessed Dementia Rating Scale (MBDRS) (Blessed, et al., 1968). This method is being used in addition to chart review and healthcare professional reporting since the presence of dementia is underreported in the medical chart. Using the MBDRS is a validated measure to assess for the presence of pre-existing cognitive impairment in persons with and without superimposed delirium (Froehlich, et al., 1998; Pisani, et al., 2003). The MBDRS is used as a screening tool and will be collected within 72 hours of hospital admission by a trained RA.

The MBDRS ranges in score from 0 to 17, with higher scores indicating increasing impairment. There are a total of 8 questions, asked to the informal caregiver, rating memory and performance over the past six months, each scored as 0 (no impairment), 0.5 (some impairment), or 1.0 (severe
impairment or inability to perform). The questions asked focus on performing usual household tasks, dealing with small sums of money, and the ability to recall recent events or recognize familiar faces. In addition to questions involving memory and performance, the MBDRS also includes three questions pertaining to activities of daily living, each rated on a scale of 0 to 3, with 3 indicating the most severe impairment. The ADLs included on the MBDRS are eating, dressing, and toileting. Each rating has a small description, for example, a rating of 2 with dressing is described as: “Wrong sequences, forgets items, requires much assistance” (Blessed, et al., 1968). The time frame for rating ADL impairment is within the past two weeks prior to the current illness, so that the individual is not based on the present illness, which may impact their current abilities.

Delirium presence. Delirium will be defined according to the Confusion Assessment Method (CAM) (Inouye, et al., 1990a). The CAM is a valid and reliable measure to detect delirium in hospitalized elders with and without pre-existing cognitive impairment related to dementia, having sensitivity between 94%-100% and specificity between 90%-95% (Inouye, et al., 1990a; Pompei, et al., 1995; Wong, et al., 2010). Delirium will be assessed within 48 hours of hospital admission and daily by trained research assistants in the parent study and recorded as either present or absent.

The CAM features of delirium include: 1) acute onset and fluctuating course, 2) inattention, 3) disorganized thinking, and 4) altered level of consciousness (Inouye, et al., 1990a). Delirium is determined to be present if both symptoms 1 and 2, and either 3 or 4 are present. Determining the presence of these symptoms is based on patient and nurse interview, as well as chart review in the parent study as conducted by a trained RA. Subsyndromal delirium, for the purpose of this study, will be defined as at least two features of delirium according to the CAM. Typically subsyndromal delirium is defined as having a minimum of one feature of delirium (Cole, et al., 2003). A conservative estimate of
subsyndromal delirium is used within this study to account for the possibility of overlapping features of dementia and delirium.

**Delirium severity.** Delirium severity will be measured according to the delirium rating scale (DRS-R-98). The DRS-R-98 is a 16 item scale divided into two sections, a diagnostic section with 3 questions and a 13-item severity index, with a total score range of 0-39 (Trzepacz, et al., 2001; Wong, et al., 2010). Sensitivity of this scale ranges from 85%-100%, while specificity is between 77%-93% (Trzepacz, et al., 2001). This scale is a valid instrument in detecting delirium severity in persons with dementia. Delirium severity is measured within 48 hours of admission.

The DRS-R-98 assesses perceptual disturbances, hallucinations, delusions, motor agitation or retardation, orientation, attention, short-term and long-term memory, visuospatial ability, psychical disorder, sleep-wake cycle disturbances, and affect within the 13-item severity index. A trained research assistant within the study completes the DRS-R-98 after patient interview. Additional information from formal healthcare providers and chart review is used to assess for each feature of delirium as needed. Each feature is rated on a scale of 0 to 3, with higher scores indicating increasing delirium severity. The DRS-R-98 also features descriptions of each rating for each of the categories to allow for standardized scoring. For example, a score of 1 in the category of sleep-wake disturbance is described as “Mild sleep continuity disturbance at night or occasional drowsiness during the day” while a score of 3 is described as “Severe disruption of sleep-wake cycle (e.g., day-night reversal of sleep-wake cycle or severe circadian fragmentation with multiple periods of sleep and wakefulness or severe sleeplessness.)” (Trzepacz, et al., 2001). The diagnostic items include temporal onset of symptoms, fluctuation of symptoms, and the degree to which symptoms can be attributed to a physiological or medical condition (Trzepacz, et al., 2001). These items are also scored on the same 0 to 3 scale.
**Delirium motoric subtype.** Delirium motoric subtype will be assessed according to the DRS-R-98. The DRS-R-98 includes two items on motoric presentation of delirium, motor agitation or retardation (Trzepacz, et al., 2001). A score of ≥1 on DRS-R-98 items number 7 and 8 have been used to indicate hypoactivity and/or hyperactivity respectively. This scale has been determined to be the most accurate measure of hypoactive delirium with a sensitivity of 57% and a specificity of 89% (de Rooij et al., 2006; Meagher, Moran, Raju, Gibbons, et al., 2008). A trained RA assesses delirium motoric subtype within the parent study in 72 hours of hospital admission and daily during hospitalization. Information to determine the delirium motoric subtype will be obtained from patient and informal caregiver interview, and supplemented with formal healthcare provider interview and chart review as needed.

The DRS-R-98 measures both motor agitation (hyperactivity) and motor retardation (hypoactivity) on a 0 to 3 point scale, with increasing scores indicating more severe symptoms. Motor agitation is described on the DRS-R-98 according to the following ratings:

0. No restlessness or agitation
1. Mild restlessness of gross motor movements or mild fidgetiness
2. Moderate motor agitation including dramatic movements of the extremities, pacing, fidgeting, removing intravenous lines, etc.
3. Severe motor agitation, such as combativeness or a need for restraints or seclusion

Motor retardation is measured in a similar way according to the following criteria and features:

0. No slowness of voluntary movements
1. Mildly reduced frequency, spontaneity or speed of motor movements, to the degree that may interfere somewhat with the assessment.
2. Moderately reduced frequency, spontaneity or speed of motor movements to the degree that it interferes with participation in activities or self-care

A score of ≥1 on DRS-R-98 items motor agitation and motor retardation will be used to indicate hyperactive and/or hypoactive respectively. Mixed delirium will be defined as meeting both the definition of hypoactive and hyperactive delirium on the DRS-R-98.

<table>
<thead>
<tr>
<th>Table 3.1 Patient Measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Measure</td>
</tr>
<tr>
<td>Dementia Presence</td>
</tr>
<tr>
<td>Delirium Presence</td>
</tr>
<tr>
<td>Delirium Severity</td>
</tr>
<tr>
<td>Delirium Motoric Subtype</td>
</tr>
</tbody>
</table>

**Informal Caregiver Measures**

Informal caregiver measures will be collected in a researcher-developed instrument after the hospitalization period including relationship to patient, living arrangement between the informal caregiver and patient, informal caregiver education, and informal caregiver experience with delirium (See Appendix A). To date no studies have examined informal caregiver correlates of reporting of symptoms of delirium. Correlates will be drawn from the literature surrounding informal caregiver recognition of dementia and formal healthcare provider recognition of delirium in persons with and without pre-existing dementia. Considering the overlap between dementia and delirium, this is a plausible context to identify potential correlates of delirium recognition. Interviews with informal caregivers are a strategy used to enhance recognition of dementia by professional healthcare providers (Knopman, 1998; Tierney, Szalai, Snow, & Fisher, 1996) (Table 2).
Relationship. Type of relationship between the patient and informal caregiver will be categorized as follows: husband, wife, son/son-in-law, daughter/daughter-in-law, and other. This is to account for gender differences in the recognition of subtle mental status changes as seen in recognizing subtle symptoms of Alzheimer’s and related disorders and disclosing cancer diagnoses (Hayes, et al., 2010; Hilton, et al., 2009). For the purpose of this study, relationship will be explored as a potential predictor in the reporting of delirium symptoms. This information will be collected and analyzed as nominal, categorical data.

Living arrangement. Living arrangement between the informal caregiver and person with dementia will also be collected as a potential covariate (McLoughlin, et al., 1996). This binary, categorical variable will be measured as whether the patient and informal caregiver reside together or separately.

Informal caregiver educational level. Amount of education has been identified as a correlate to identification of symptoms of dementia (Carpenter, Zoller, Balsis, Otilingam, & Gatz, 2011; Ross, et al., 1997). Education will be measured as a categorical variable as one of the following: did not graduate high school, graduated high school, and education beyond high school.

Informal caregiver knowledge of and experience with delirium. Caregiver experience with delirium will be assessed using a researcher-developed tool. Informal caregivers will be asked if they are familiar terms acute confusion or delirium and what they mean to them. Persons who have cared for a person previously with dementia or have had another family member with dementia are more likely to recognize symptoms associated with dementia (Ross, et al., 1997; Werner, 2003). This data will be collected as both a binary, categorical variable (yes/no) and as additional qualitative, descriptive data describing their experience.

Outcome Measures
**Detection and recognition of delirium.** The primary outcome measure in this study will be informal caregiver detection and recognition of symptoms of delirium collected within 48 hours of hospital admission by a trained research assistant within the parent study (Table 2). Informal caregiver detection of delirium symptoms will be compared to the presence or absence of delirium as measured by a trained research assistant.

The Family Confusion Assessment Method (FAM-CAM) is a tool used to measure informal caregiver detection of symptoms of delirium. In addition to assessing the four key features of delirium according to the CAM, the FAM-CAM also assesses disorientation, perceptual disturbances, and inappropriate behaviors. The FAM-CAM, as used within END-DSD, assesses for informal caregiver detection of delirium symptoms up to one week prior to the hospitalization and within 48 hours of hospital admission.

This tool has not been validated for informal caregiver recognition of delirium in hospitalized older adults with dementia, but has been used in the home healthcare setting (Steis, Evans, et al., 2012). The initial validity study examined convergent validity of the FAM-CAM to interviewer-rated assessment using the CAM in a total of 52 dyads. The point prevalence of delirium in this study was 13% (7/52). The study found good agreement between the FAM-CAM and CAM (Kappa=0.85, 95% Confidence Interval=0.65-1.0, Sensitivity=88%, Specificity=98%) (Steis, Evans, et al., 2012).

**Informal caregiver hospital experience.** Qualitative, descriptive data will be collected regarding the informal caregiver’s perspective of the hospital experience for a person with pre-existing dementia and potentially delirium. In addition, reporting of symptoms and communication between the informal caregiver and formal healthcare providers will be explored (See Appendix A).
Table 3.2 Informal Caregivers and Outcomes Measures

<table>
<thead>
<tr>
<th>Informal Caregiver Measures</th>
<th>When</th>
<th>How</th>
<th>Purpose</th>
<th>Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship</td>
<td>Within 7 days of discharge</td>
<td>Proxy Screening Tool</td>
<td>Predictive, Correlational</td>
<td>2</td>
</tr>
<tr>
<td>Living Arrangement</td>
<td>Within 7 days of discharge</td>
<td>Proxy Screening Tool</td>
<td>Predictive, Correlational</td>
<td>2</td>
</tr>
<tr>
<td>Education</td>
<td>Within 7 days of discharge</td>
<td>Researcher Developed Tool</td>
<td>Predictive, Correlational</td>
<td>2</td>
</tr>
<tr>
<td>Knowledge of delirium</td>
<td>Within 7 days of discharge</td>
<td>Researcher Developed Tool</td>
<td>Predictive, Correlational</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome Measures</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Detection of Delirium Symptoms</td>
<td>Within 48 hours of admission</td>
<td>The Confusion Assessment Method-Family (CAM-FAM)</td>
<td>Outcome</td>
<td>1,2,3</td>
</tr>
<tr>
<td>Reporting of Symptoms</td>
<td>Within 7 days of discharge</td>
<td>Researcher Developed Tool</td>
<td>Exploratory</td>
<td>3</td>
</tr>
</tbody>
</table>

Data Collection and Management

All data except for the post-hospitalization telephone interview will be collected by RAs within the parent study and will be extracted from the END-DSD database for use. Parent study data are initially collected using pencil and paper, and are then entered and managed in an electronic database, RED-CAP. The parent study project director will supervise transfer of appropriate data to the PI in concordance with the data safety and monitoring plan, ensuring patient confidentiality.

Administration of the post-hospitalization questionnaire to the informal caregiver will take place via a telephone interview conducted within seven days post-hospital discharge of the patient. It is anticipated that administration of the questionnaire will take 20 minutes. Data from the questionnaire will be transcribed using pencil and paper and then stored in an electronic file using Microsoft Excel. This database will be locked using a secure password and kept on a computer in a locked office.

Protection of Human Subjects
Subjects participating in this study are also participants in the parent study END-DSD. The proposed risks and benefits for this study are similar to the parent study. Approval for the parent study has been obtained from The Pennsylvania State University Institutional Review Board (IRB) and both of the individual acute care facility IRBs. Additional approval for of this project was obtained through the same IRBs. Offices of Research Protections (ORP) guidelines are followed to maintain privacy and confidentiality including Health Information Portability and Protection Act (HIPPA) rules and regulations in this vulnerable population. Data will be obtained from the following sources: patient, informal caregiver, hospital staff, and chart review. Consent is obtained in the parent study from the patient and informal caregiver at the time of enrollment in the parent study. Implied consent for hospital staff participation in this study has been obtained at all sites.

Potential risks. Potential risks to subjects are minimal, but may include increased anxiety and fatigue due to initial and daily assessment. Although daily assent is obtained, if at any time the hospitalized patient appears anxious, fatigued, or refuses to participate, the RA will immediately stop the evaluation. Minimal risks are also expected for the informal caregivers, but may include potential anxiety and fatigue related to questioning. If at any point in time the informal caregiver requests to end the telephone interview, the PI will follow with their desire. In the event that an informal caregiver would experience severe distress or need additional support beyond the scope of this study, local telephone numbers for Alzheimer’s disease support groups and the Area Agency on Aging would be provided.

Data safety and monitoring plan. A data safety and monitoring plan (DSMP) was developed in the parent study, END-DSD. The DSMP is composed of three individuals, a physician, nurse, and clinical researcher, who are not directly involved with the study. They will provide oversight and monitoring of the proposed study to address any potential risks to the vulnerable population of interest from
participation in the study. The members of the DSMP will meet yearly to evaluate data quality and timeliness, subject recruitment, accrual and retention, and subject risk versus benefit. In addition, data will be reviewed by the committee every six months and additional meetings will be held in the event of unusual circumstances or if there is an occurrence of an adverse event. The committee will maintain confidentiality of all participants during the meetings.

**Potential benefits.** Although there are no known potential benefits to participants in this study, it is the hope of the PI that information obtained in this research will help to enhance early recognition and management of delirium in the future, preventing adverse outcomes associated with delirium in this vulnerable population.

**Limitations.** The main limitation within this study surrounds the use of the FAM-CAM tool. Use of this tool may sensitize informal caregivers to symptoms of during hospitalization and they may be more likely to then subsequently report these symptoms during the post-hospitalization interview. In addition, the post-hospitalization interview is a retrospective measure and subject to threats of validity associated with this type of data.

**Data Analysis**

This descriptive, exploratory study will use Kappa coefficients, logistic regression and qualitative analysis of both quantitative and qualitative data to address the specific aims. A significance level will be set at p-value less than 0.05 for all of the statistical tests. SAS Analytic Software (version 9.3) will be used for all statistical tests unless otherwise stated.

**Analysis for Specific Aim 1**

Aim 1: To compare the agreement between informal caregiver assessment of delirium, the Family Confusion Assessment Method (FAM-CAM) to trained research assistant (RA) assessment of
delirium using the Confusion Assessment Method (CAM) in hospitalized older adults with underlying dementia. A Kappa Coefficient (Kappa) will be used to provide a measure of the degree to which informal caregivers and trained research assistant agree in their rating for the presence of delirium in hospitalized older adults within 24-48 hours of hospital admission. SAS will be used to provide a simple Kappa estimate and the lower and upper bounds of the 95% confidence interval. Kappa will provide an estimate of the extent of agreement between informal caregiver and RA ratings of delirium. Kappa generally ranges from 0 to 1; the closer the value is to 1, the higher agreement between the raters. Kappa can also range from -1 to 1, with negative values indicating that agreement is less than would be expected by chance.

Table 3.3 Possible Outcomes for Trained RA and Informal Caregiver Ratings of Delirium Using the CAM and FAM-CAM

<table>
<thead>
<tr>
<th></th>
<th>Research Assistant</th>
<th>Informal Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Absent</td>
<td>Present</td>
</tr>
<tr>
<td>Absent</td>
<td>X_{00}</td>
<td>X_{01}</td>
</tr>
<tr>
<td>Present</td>
<td>X_{10}</td>
<td>X_{11}</td>
</tr>
<tr>
<td>Total</td>
<td>M_{0}</td>
<td>M_{1}</td>
</tr>
</tbody>
</table>

Note: 0 refers to delirium being absent, 1 represents delirium being present

The Kappa Coefficient is also known as Cohen’s κ after the developer Jacob Cohen (Machin, Campell, & Walters, 2007). This statistic was developed to account for the chance agreement between raters when using binary choices. Since there is a limited amount of options, two, in this type of data there is a high probability two individuals may agree by chance. The κ statistic is computed as the proportion of cases that the raters agree on minus the proportion of cases they are likely to agree on by chance, scaled so that if the raters agree all the time then κ=1.

\[
K = \frac{P_{\text{Agree}} - P_{\text{Chanc}}}{1 - P_{\text{Chanc}}}
\]

If κ=1 then there is perfect agreement, and when κ=0 the agreement is no better than it would be by chance (Machin, et al., 2007). There are several limitations to using a Kappa coefficient. First, the
maximum value of $\kappa$ is based on unbiased observer agreement. Second, for any level of agreement as the number of categories decreases $\kappa$ will increase so this statistic should only be used for comparisons when the number of categories is the same. Kappa assumes marginal distributions and finally $\kappa$ does not test a null hypothesis so there is no associated p-value. For the purpose of this study and data analysis, ‘yes’ answers will be coded as 1, with ‘no’ answers being coded 0.

**Item agreement.** Agreement on the CAM and the CAM-FAM extends beyond presence (1) or absence (0) of delirium. Item agreement for the main features of delirium will also be conducted. For the purpose of this data analysis, inter-rater agreement will also be determined by calculating a Kappa score. The Confusion Assessment Method had four-items, each scored as either ‘yes’ or ‘no’; in contrast to the FAM-CAM which scores items as either ‘yes’, ‘no’, ‘don’t know’, or ‘refused’. To account for the differences in scoring and to calculate appropriate Kappa scores, items scored as either ‘don’t know’ or ‘refused’ will be given a value of 0; items scored as ‘yes’ will be coded as a 1 and ‘no’ as 0. Kappa in this case will range from -0 to 1, with scores closer to 1 indicating better agreement and scores closer to 0 indicating less agreement between informal caregivers and research assistants.

**Sample Size**

For the purpose of this study, sample size is based on the precision of the confidence interval for Cohen’s Kappa Coefficient. Using nQuery Advisor 7.0 software, a 95% confidence interval was determined to have limits of -/+ 0.25 for a sample size of 50 patients and informal caregivers. Although this number is not ideal, it is the best available estimate. Ideal limits for a 95% confidence interval are -/+0.10, which would need an estimated enrollment of at least 200 patients and informal caregivers. Based on current enrollment this is an unobtainable sample size.

**Analysis for Specific Aim 2**
Aim 2: To evaluate factors associated with reporting of symptoms of delirium by informal caregivers, including: dementia stage; delirium severity; delirium motoric subtype; relationship between the informal caregiver and care recipient; living arrangement between the informal care caregiver and care recipient; education level of the informal caregiver; and pre-existing knowledge of or experience with delirium. These characteristics are of both the hospitalized older adult and the informal caregiver. These variables will serve as potential characteristics in explaining reporting of symptoms of delirium by informal caregivers as measured using the CAM-FAM. The dependent, or response, variable in this case has two categories. The first is that both the informal caregiver rates the hospitalized older adult as having delirium (=1). The second category is that the informal caregiver rates the individual as not having delirium (=0). This outcome was chosen because it is important to understand what characteristics make informal caregivers more or less likely to report symptoms of delirium in the acute care setting, independent of formal healthcare providers.

To further understand why logistic regression was chosen for this study, methods for dealing with the relationship between variables will be explored. Correlation and regression are the two main techniques for examining the relationship between two or more continuous variables (Machin, et al., 2007). Correlation uses a correlation coefficient to represent the strength of the relationship between two variables. In contrast, regression is used when looking for the dependence of one variable, the dependent variable, on another variable, the independent variable. There are two types of regression, linear and logistic. Linear regression is used when the dependent variable is continuous; logistic regression is used when the dependent variable is binary. For the purpose of this study, delirium presence was chosen as the dependent variable. Delirium presence is either negative or positive; a binary variable, so logistic regression is the method of choice. For the purpose of this discussion, delirium presence will be coded as a 1, delirium absence as a 0.
Understanding logistic regression begins with understanding linear regression. The following equation describes a relationship between the dependent variable, \( y \), and the independent variable, \( x \):

\[
y = \alpha + \beta x
\]

In this equation, \( \alpha \) represents the value of the dependent variable when \( x = 0 \) and \( \beta \) is the slope of the line, so that for every unit increase in \( x \), \( y \) will change by \( \beta \) units. There are several assumptions underlying the use of a linear regression model (Machin, et al., 2007), first the relationship between \( x \) and \( y \) must be a linear relationship. Second, the prediction error must be unrelated to the predicted value of \( y \). Another assumption is that the residual values of \( y \) must be normally distributed. And finally, the residual values are independent of each other. The residual value determines if \( x \) is truly influencing \( y \). The linear regression model can be extended to include multiple factors that may influence the \( y \) variable; in that case it then becomes a multiple regression model:

\[
y = \alpha + \beta_1 x_1 + \ldots + \beta_k x_k + \epsilon
\]

In this case, \( x_1 \) represents the first independent variable, up to \( x_k \), or the \( k \)th variable. The term \( \epsilon \) refers to the error. The same assumptions that undergird linear regression also apply to multiple regression.

This basic understanding of linear and multiple regression will allow for further discussion of logistic regression. As stated previously the main difference between these two analyses is that in logistic regression, also known as binary logistic regression, the dependent variable is binary, not continuous as in linear regression. The logistic regression model is written with the assumption that the probability of a positive result for \( y \) with a certain variable of \( x \) is \( \pi \). The logistic model is:

\[
\log \left( \frac{\pi}{1 - \pi} \right) = \alpha + \beta x
\]
The right side of the logistic regression equation is comparable to the linear regression equation. The left side has been transformed to allow for the value of the dependent variable to range from $-\infty$ to $+\infty$. This transformation essentially converts the binary dependent variable to a continuous dependent variable as in linear regression ensuring that the probability, which is the desired estimate in this equation, lies between 0 and 1.

Similarly to linear regression, logistic regression can include more than one independent variable to multiple logistic regression. The equation for multiple logistic regression is:

$$\log\left(\frac{\pi}{1-\pi}\right) = \alpha + \beta_1 x_1 + \ldots + \beta_k x_k$$

The multiple logistic regression equation can also be written as an expression of probabilities using mathematical transformations of the log function:

$$p = \frac{\exp(a + b_1 x_1 + \ldots + b_k x_k)}{1 + \exp(a + b_1 x_1 + \ldots + b_k x_k)}$$

For the purpose of this study $p$ would be the probability of an informal caregiver recognizing symptoms of delirium based on a number of independent factors such as those being explored in this study.

For the purpose of this study and to explore the effects of both forward stepwise regression and backwards-stepwise regression on the model, both methods will be used to build a model. The final model will be determined based on the fit of each individual model. Forward stepwise regression helps minimize the effects of collinearity, which is common when performing logistic regression. Collinearity occurs when two or more independent variables are highly related which may impact the precision of the estimated coefficients within the model (Bagley, White, & Golomb, 2001). This will result in a loss of statistical significance and impact the precision of the model. To minimize the impact of collinearity forward stepwise regression will be used. This is a process of building the logistic model from the
‘ground-up’ or adding variables one at a time to assess the significance of each variable on the model. Backwards-stepwise regression is the process of including all variables in the model from the start and then subtracting each statistically, non-significant variable from the model. Both methods will be evaluated based on the exploratory nature of this study and to account for the interaction between variables in a logistic regression model.

There are two methods for assessing the fit of the model, or to determine how well the model predicts what characteristics of informal caregivers and patients are likely to impact informal caregiver recognition of delirium symptoms according to the FAM-CAM. These two methods include validation and cross-validation. Validation includes replication of the study to validate the model. This is not feasible within the scope of this project.

Cross-validation includes partitioning subjects into thirds, with two-thirds of the subjects being used to build or create the logistic regression model with the other third of the subjects being used to validate the model or perform a distinct validation study. Cross-validation cannot be used to evaluate model performance in this study due to the small sample size. Although the limits of this study do not allow for model performance testing, these methods can be used in further research to test the model.

**Analysis for Specific Aim 3**

The final aim of this study is to describe the hospital experience, and the detection and recognition of symptoms of delirium, from the perspective of informal caregivers of persons with pre-existing dementia. Little is known about the reporting of symptoms of delirium between informal caregivers of persons with pre-existing dementia and formal healthcare providers. Data collected during the post-hospitalization telephone interview will be analyzed quantitatively and qualitatively to understand the process of communication of symptoms between these two groups. This survey tool was pilot tested in a population of 3-6 subjects to gain a further understanding of how the data may be
reported from the perspective of the informal caregiver. The pilot study allowed for modification of the
tool.

**Summary: Chapter 3**

The proposed study will assess the agreement between informal caregiver and trained research
assistant recognition of delirium. This study is using a sample of participants concurrently enrolled in a
larger, randomized clinical trial. Using several baseline measures collected within the larger parent
study, and exploratory descriptive measures unique to the proposed study will allow for a detailed
analysis of informal caregiver reporting of delirium symptoms and potential characteristics of the
informal caregiver and hospitalized older adult that may impact reporting of these symptoms. The
hospital experience from the perspective of the informal caregiver will also be explored, including
communication between informal caregivers and formal healthcare providers.
Chapter 4

Results

Introduction

The sample characteristics and an overview of the analysis are provided in this chapter. The results will be presented based on the specific aims of the study.

Sample Characteristics

The sample consisted of hospitalized older adults over the age of 65 with a baseline of dementia and their informal caregivers enrolled within 48 hours of hospital admission (Table 4.1).

| Table 4.1 Demographic Characteristics of Patients with Dementia on Admission |
|---------------------------------|-----------------|-----------------|-----------------|
| **Patient Characteristics**     | **Overall (N=38)** | **Delirium Positive (N=6)** | **Delirium Negative (N=32)** |
| Age, Mean +/- SD (Range)        | 86.63 +/- 4.77 (74-96) | 89.00 +/- 4.10 (81-93) | 86.19 +/- 4.81 (74-96) |
| Gender, N (%)                   |                 |                 |                 |
| Female                          | 27 (71%)        | 5               | 22              |
| Male                            | 11 (29%)        | 1               | 10              |
| Race, N (%)                     |                 |                 |                 |
| Caucasian                       | 38 (100%)       | 6 (100%)        | 32 (100%)       |
| Marital Status, N (%)           |                 |                 |                 |
| Widowed                         | 24 (63%)        | 6               | 18              |
| Married                         | 13 (34%)        | 0               | 13              |
| Single                          | 1 (3%)          | 0               | 0               |
| Education in Years, Mean +/- SD (Range) (N=36) | 12.11 +/- 2.33 (8-18) | 12.20 +/- 2.49 (9-16) | 12.10 +/- 2.34 (8-18) |
| Occupation, N (%) (N=37)        |                 |                 |                 |
| Manufacturing                   | 7 (19%)         |                 |                 |
| Professional, Scientific, and Technical Services | 4 (11%)        |                 |                 |
| Health Care and Social Assistance | 4 (11%)     |                 |                 |
| Other                           | 22 (59%)        |                 |                 |
| Living Arrangement, N (%)       |                 |                 |                 |
| Lives with Spouse               | 10 (26%)        | 0               | 10              |
| Lives with Another              | 12 (32%)        | 3               | 9               |
| Lives Alone                     | 7 (18%)         | 5               | 2               |
| Lives in Personal Care or       | 6 (16%)         | 1               | 5               |
The baseline demographic data (Table 4.1) was collected during screening and enrollment of the patient and informal caregiver into the parent study Early Nurse Detection of Delirium Superimposed on Dementia (END-DSD). The total sample included 38 patient and informal caregiver dyads for the purpose of patient baseline characteristics. The point prevalence for delirium in this study was 16% (6/38). The patients had a mean age of 87 years with a range from age 74-96 years old, with the delirium positive group being older on average by three years compared to the delirium negative group. The majority of patients were female, widowed, and lived with someone else, which included living in a personal care facility or nursing home. All were Caucasian. Education did not differ significantly across the groups of delirium positive and delirium negative. The occupational background of the sample was diverse with seven persons having worked mainly in a Manufacturing position; four persons in Professional,
Scientific, and Technical Services; four persons in Health Care and Social Assistance, with the remainder in other occupations.

### Table 4.2 Demographic Characteristics of Informal Caregivers

<table>
<thead>
<tr>
<th>Informal Caregiver Characteristics</th>
<th>Overall N=23</th>
<th>Delirium Positive N=5</th>
<th>Delirium Negative N=18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Relationship, N (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>4 (18%)</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Adult Child</td>
<td>18 (78%)</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Other</td>
<td>1 (4%)</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Lives with Patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8 (35%)</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>No</td>
<td>15 (65%)</td>
<td>3</td>
<td>12</td>
</tr>
<tr>
<td>Familiar with Phrase ‘Acute Confusion’ N (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7 (18%)</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>16 (82%)</td>
<td>3</td>
<td>13</td>
</tr>
<tr>
<td>Familiar with Term ‘Delirium’</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18 (78%)</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>5 (22%)</td>
<td>1</td>
<td>17</td>
</tr>
<tr>
<td>Education N (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did Not Graduate High School</td>
<td>4 (17%)</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Graduated High School</td>
<td>10 (44%)</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Beyond High School</td>
<td>9 (39%)</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>

Overall, the sample characteristics indicate that the individuals with dementia and delirium were more vulnerable than those with dementia alone. The persons with dementia and delirium had higher Modified Blessed Dementia Rating Scale (MBDRS) Scores, increased Clinical Dementia Rating (CDR) Scale Scores, and lower Mini-Mental State Examination (MMSE) Scores.

Characteristics of informal caregivers are reported in Table 4.2. Data for informal caregiver characteristics was collected in a post-hospitalization telephone call, 23 out of the 38 total informal caregivers participated in this telephone interview. There were a total of 15 informal caregivers who did not complete the post-hospitalization telephone call. The reasons included: refusal to allow calling after hospitalization (N=2), refusal to complete survey (N=3), unable to contact (N=9), and patient status
changed to terminal (N=1). The majority of caregivers (N=18, 78%) were adult children; this is consistent with other research on informal caregivers (Steis, Evans, et al., 2012).

Informal caregivers reported that they were more familiar with the term *delirium* than the phrase *acute confusion* (N=18, 78% versus N=7, 18%). This is not a measure of their knowledge of the definitions of *acute confusion* or *delirium*. Additional characteristics of informal caregivers are provided in Table 4.2.

**Data Analysis**

Quantitative and qualitative analysis were used in this exploratory, descriptive study. The main quantitative analyses used included descriptive and comparative statistics, correlation coefficients specifically calculation of Kappa Coefficients, and logistic regression. Descriptive and comparative statistics were calculated using the Statistical Package for the Social Sciences (SPSS) 17.0 for Windows. The remainder of the quantitative analyses was performed via SAS Analytic Software (Version 9.3). Data was obtained from both the parent study, END-DSD, and from informal caregiver reports. Qualitative analyses were done using line-by-line coding and thematic analysis as described in Chapter 3. The data source for the qualitative data included informal caregiver report using the semi-structured telephone interview guide. The END-DSD Project Director (PD) per the informal caregivers request conducted two interviews.

**Overall Results**

**Specific Aim 1**

To compare the agreement between informal caregiver assessment of delirium, the Family Confusion Assessment Method (FAM-CAM) to trained research assistant (RA) assessment of delirium using the Confusion Assessment Method (CAM) in hospitalized older adults with underlying dementia.
The purpose of this aim was to explore agreement between research assistant and informal caregiver ratings of delirium using the FAM-CAM, which has not previously been used in hospitalized older adults with pre-existing dementia. Correlation coefficients, Kappa in this particular case due to the binomial nature of delirium, were calculated.

The total sample size included 38 research assistant (RA) and informal caregiver (IC) ratings of delirium for comparison with six identified cases of delirium as evaluated by the research assistant (gold standard). Overall agreement for full delirium (Table 4.3) was poor (K=-0.07; 95% Confidence Interval equal to 0.35-0.21). As seen in Table 4.3, the Kappa value is negative and the confidence interval includes zero, which statistically suggests that there was a better chance that the two raters would agree just by chance on delirium ratings. There was only one case where both the RA and IC agreed that the persons with dementia had delirium using the CAM and FAM-CAM tools, respectively (Sensitivity=16.67%). The specificity, identification of true negative cases, was at a higher level of 75.00%.

<table>
<thead>
<tr>
<th>Informal Caregiver Rating</th>
<th>Researcher Rating</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Delirium</td>
<td>No Delirium</td>
<td>24, 63.16%</td>
</tr>
<tr>
<td></td>
<td>Delirium</td>
<td>8, 21.05%</td>
</tr>
<tr>
<td>Delirium</td>
<td></td>
<td>5, 13.16%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1, 2.63%</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>29, 76.32%</td>
</tr>
</tbody>
</table>

**Table 4.3 Comparison of Informal Caregiver and Researcher Ratings of Full Delirium (N=38)**

In addition to calculation of Kappa Coefficients for full delirium, the agreement for subsyndromal delirium was also conducted (Table 4.4). Subsyndromal delirium is defined as having two or more features of delirium using the CAM, but not meeting full criteria for delirium. There were a total of two cases of subsyndromal delirium according to the RA, with seven cases of subsyndromal delirium...
according to informal caregivers. Agreement for subsyndromal delirium was also poor (Kappa=-0.02, 95% Confidence Interval equal to -0.33-0.29). Again, the Kappa Coefficient and the corresponding confidence interval suggest that there was a greater agreement by chance. The sensitivity remains poor, with improved specificity.

| Table 4.4 Comparison of Informal Caregiver and Researcher Ratings of Subsyndromal Delirium |
|-----------------------------------------------|-----------------|-----------------|
| Researcher Rating                              | Informal Caregiver Rating | Total           |
| No Delirium                                    | No Delirium | Subsyndromal Delirium | 29, 76.32% |
|                                                | 22, 57.89% | 7, 18.42%           | 29, 76.32% |
| Subsyndromal Delirium                          | 7, 18.42% | 2, 5.26%            | 9, 23.68%  |
| Total                                          | 29, 76.32% | 9, 23.68%           | 38          |
| Sensitivity (True Positives)                   | 22.22%     |                  |
| Specificity (True Negatives)                   | 75.86%     |                  |
| Kappa (95% Confidence Interval)                | -0.02 (-0.33-0.29) |                |

Performing Kappa Coefficient analysis for combined full and subsyndromal delirium improves agreement somewhat (K=0.31) (Table 4.5), although this is certainly not considered to represent a high level of agreement.

| Table 4.5 Comparison of Informal Caregiver and Researcher Ratings of Full and Subsyndromal Delirium (N=38) |
|-----------------------------------------------|-----------------|-----------------|
| Researcher Rating                              | Informal Caregiver Rating | Total           |
| No Delirium                                    | No Delirium | Combined Delirium | 23, 60.53% |
|                                                | 15, 39.47% | 8, 21.05%          | 23, 60.53% |
| Combined Delirium                              | 5, 13.16% | 10, 26.32%         | 15, 39.47% |
| Total                                          | 20, 52.63% | 18, 47.37%          | 38          |
| Sensitivity (True Positives)                   | 66.67%     |                  |
| Specificity (True Negatives)                   | 65.22%     |                  |
| Kappa (95% Confidence Interval)                | 0.31 (0.01-0.61) |                |

In addition to determining overall agreement, item agreement analysis was also conducted (Table 4.6). Informal caregivers and research assistants had agreement different than zero on delirium features including acute onset, inattention, and disorganized thinking as evidenced by Kappa greater than 0.30 and a 95% Confidence Interval not containing zero.
Table 4.6 Sensitivity, Specificity, and Kappa for Individual CAM versus FAM-CAM Features (N=38)

<table>
<thead>
<tr>
<th>Individual Features</th>
<th>Sensitivity</th>
<th>Specificity</th>
<th>Kappa (95% Confidence Interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N, %</td>
<td>N, %</td>
<td></td>
</tr>
<tr>
<td>Acute Onset</td>
<td>11, 100%</td>
<td>14, 51.85%</td>
<td>0.38 (0.17-0.59)</td>
</tr>
<tr>
<td>Fluctuating Course</td>
<td>8, 61.54%</td>
<td>8, 47.06%</td>
<td>0.08 (-0.26-0.43)</td>
</tr>
<tr>
<td>Inattention</td>
<td>14, 73.68%</td>
<td>12, 66.67%</td>
<td>0.08 (0.11-0.70)</td>
</tr>
<tr>
<td>Disorganized Thinking</td>
<td>6, 54.55%</td>
<td>23, 88.46%</td>
<td>0.45 (0.13-0.77)</td>
</tr>
<tr>
<td>Altered Level of Consciousness</td>
<td>4, 57.14%</td>
<td>15, 51.72%</td>
<td>0.06 (-0.20-0.31)</td>
</tr>
</tbody>
</table>

The Family Confusion Assessment Method elicits additional information regarding delirium symptoms from informal caregivers including assessment for presence of disorientation, hallucinations, and inappropriate behaviors such as combativeness or wandering. Kappa coefficients were calculated using the original FAM-CAM algorithm with the addition of each individual FAM-CAM questions and then using all features asked within the tool.

Table 4.7 gives the agreement of the FAM-CAM items as answered by the informal caregiver compared to the research assistant rating for delirium using the original CAM algorithm and then with the addition of sequential items that impact the sensitivity, specificity, and Kappa of the FAM-CAM. These items are additional questions asked within the FAM-CAM tool not asked by the Confusion Assessment Method used by research assistants. These items include: disorientation, hallucinations, and inappropriate behaviors. The FAM-CAM question combination that has the highest Kappa (0.32) is the original delirium algorithm in the CAM with the additional feature of disorientation (Table 4.7).

Table 4.7 Sensitivity, Specificity, and Kappa for Full Delirium per Family Confusion Assessment Method Features (N=6)

<table>
<thead>
<tr>
<th>FAM-CAM Questions</th>
<th>Sensitivity</th>
<th>Specificity</th>
<th>Kappa (95% Confidence Interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Original CAM Algorithm:</strong> Acute Onset, Fluctuating Course, Inattention, Disorganized Thinking, and Altered Level of Consciousness</td>
<td>1, 16.67%</td>
<td>24, 75.00%</td>
<td>-0.07 (-0.35-0.21)</td>
</tr>
<tr>
<td><strong>Added:</strong> Disorientation</td>
<td>6, 100%</td>
<td>19, 59.39%</td>
<td>0.32 (0.09-0.54)</td>
</tr>
<tr>
<td><strong>Added:</strong> Hallucinations</td>
<td>1, 16.67%</td>
<td>24, 75.00%</td>
<td>-0.07 (-0.35-0.21)</td>
</tr>
</tbody>
</table>
Added: Inappropriate Behavior  
1, 16.67%  
24, 75.00%  
-0.07 (-0.35-0.21)

* Added: Disorientation, Hallucinations,  
and Inappropriate Behavior  
6, 100%  
19, 59.38%  
0.32 (0.09-0.54)

Similarly agreement was examined using the FAM-CAM versus CAM for combined full and subsyndromal with the addition of disorientation, hallucinations, and inappropriate behaviors we can see that addition of the feature of disorientation improves agreement significantly (K= -0.07 vs. 0.40) (Table 4.8). Improvement is also seen with the addition of hallucinations and inappropriate behaviors, but not to the extent of disorientation.

Table 4.8 Sensitivity, Specificity, and Kappa for Full and Subsyndromal Delirium per Family Confusion Assessment Method Features (N=15)

<table>
<thead>
<tr>
<th>FAM-CAM Questions</th>
<th>Sensitivity N, %</th>
<th>Specificity N, %</th>
<th>Kappa (95% Confidence Interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Original CAM Algorithm:</strong> Acute Onset, Fluctuating Course, Inattention, Disorganized Thinking, and Altered Level of Consciousness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Added:</strong> Disorientation</td>
<td>13, 86.67%</td>
<td>15, 56.52%</td>
<td>0.40 (0.13-0.66)</td>
</tr>
<tr>
<td><strong>Added:</strong> Hallucinations</td>
<td>10, 66.67%</td>
<td>15, 56.52%</td>
<td>0.31 (0.01-0.61)</td>
</tr>
<tr>
<td><strong>Added:</strong> Inappropriate Behavior</td>
<td>10, 66.67%</td>
<td>15, 56.22%</td>
<td>0.31 (0.01-0.61)</td>
</tr>
<tr>
<td><strong>Added:</strong> Disorientation, Hallucinations, and Inappropriate Behavior</td>
<td>13, 86.67%</td>
<td>13, 56.52%</td>
<td>0.40 (0.13-0.66)</td>
</tr>
</tbody>
</table>

Case analysis was done in addition to Kappa calculations to compare full delirium feature agreement between research assistant and informal caregiver (Table 4.9).

Table 4.9 Case Analysis Comparison between Researcher and Informal Caregiver Delirium Assessment

<table>
<thead>
<tr>
<th>Case</th>
<th>Acute Onset</th>
<th>Fluctuation</th>
<th>Inattention</th>
<th>Disorganized Thinking</th>
<th>Altered Level of Consciousness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case 1</td>
<td>RA*</td>
<td>IC**</td>
<td>RA</td>
<td>IC</td>
<td>RA</td>
</tr>
<tr>
<td>Case 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case 3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Case analysis demonstrates that research assistants and informal caregivers showed agreement on all cases on full delirium with regards to the features of acute onset and inattention. There was mixed agreement on delirium features of fluctuation, disorganized thinking and altered level of consciousness.

<table>
<thead>
<tr>
<th>Case  1</th>
<th>Case 2</th>
<th>Case 3</th>
<th>Case 4</th>
<th>Case 5</th>
<th>Case 6</th>
<th>Case 7</th>
<th>Case 8</th>
<th>Case 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal Caregiver Rating</td>
<td>FD</td>
<td>FD</td>
<td>FD</td>
<td>FD</td>
<td>FD</td>
<td>FD</td>
<td>FD</td>
<td>FD</td>
</tr>
<tr>
<td>Researcher Rating</td>
<td>ND</td>
<td>SD</td>
<td>ND</td>
<td>SD</td>
<td>FD</td>
<td>ND</td>
<td>SD</td>
<td>ND</td>
</tr>
</tbody>
</table>

Table 4.10 presents a case analysis of researcher ratings of delirium when the informal caregiver rating the patient as having full delirium as identified by the FAM-CAM tool. Case 5 is the one case where both raters agree. Four out of the remaining eight cases were rated by the research assistants as having subsyndromal delirium, while the remainder (N=4) was not rated as having delirium.

**Specific Aim 2**

To evaluate factors associated with reporting of symptoms of delirium by informal caregivers, including: dementia stage; delirium severity; delirium motoric subtype; relationship between the informal caregiver and care recipient; living arrangement between the informal care caregiver and care recipient; education level of the informal caregiver; and pre-existing knowledge of or experience with delirium. Stepwise logistic regression was applied to evaluate the significance each of these factors individually in the reporting of delirium symptoms by informal caregivers as measured using the Family Confusion Assessment Method (Table 4.11).
Table 4.11 Logistic Regression for Characteristics Impacting Detection and Recognition of Full and Subsyndromal Delirium (N=38)

<table>
<thead>
<tr>
<th>Patient Characteristic</th>
<th>Full Delirium</th>
<th></th>
<th>Combined Full and Subsyndromal Delirium</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Coefficient</td>
<td>P-Value</td>
<td>Coefficient</td>
<td>P-Value</td>
</tr>
<tr>
<td>MBDRS</td>
<td>-0.0975</td>
<td>0.4076</td>
<td>-0.2256</td>
<td>0.0768</td>
</tr>
<tr>
<td>DRS</td>
<td>-0.0267</td>
<td>0.6411</td>
<td>-0.4943</td>
<td><em>0.0041</em></td>
</tr>
<tr>
<td>Hyperactive Delirium</td>
<td>-0.2090</td>
<td>0.6533</td>
<td>-0.7446</td>
<td>0.0870</td>
</tr>
<tr>
<td>Hypoactive Delirium</td>
<td>0.2162</td>
<td>0.6770</td>
<td>-0.9368</td>
<td><em>0.0540</em></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Informal Caregiver Characteristic (N=23)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to Patient</td>
<td>0.2418</td>
<td>0.8179</td>
</tr>
<tr>
<td>Living Arrangement with Patient</td>
<td>1.2148</td>
<td>0.2849</td>
</tr>
<tr>
<td>Knowledge of Acute Confusion</td>
<td>-0.1823</td>
<td>0.8577</td>
</tr>
<tr>
<td>Knowledge of Delirium</td>
<td>-11.8403</td>
<td>0.9599</td>
</tr>
<tr>
<td>Education</td>
<td>-0.311</td>
<td>0.6477</td>
</tr>
</tbody>
</table>

*Denotes significant finding at p<0.05 significant level; MBDRS=Modified Blessed Dementia Rating Scale; DRS=Delirium Rating Severity Scale

Statistically significant patient characteristics that individually impacted the reporting of symptoms of delirium by informal caregivers included: Delirium Rating Severity Scale-Revised-98 Score, and hypoactive delirium subtype. In cases of persons with greater impairment at baseline, increased delirium severity, and the hypoactive delirium motoric subtype, informal caregivers were less likely to report symptoms of delirium per the FAM-CAM. No informal caregivers characteristics were found to be significantly associated with reporting of delirium symptoms.

Specific Aim 3

The final aim was to describe the hospital experience, and the detection and recognition of symptoms of delirium, from the perspective of informal caregivers of persons with pre-existing dementia. Qualitative analysis was done to assess the communication and reporting of symptoms between informal caregivers and formal caregivers, including physicians, registered nurses, nursing assistants, social workers, and other healthcare providers. The total sample size included 23 informal
caregiver post-hospitalization telephone interviews. Questions that did not include a large amount of qualitative data, where the answers were primarily “Yes” or “No”, were analyzed using counts and exemplars (Table 4.12). The questions asked were directly taken from the FAM-CAM tool (Steis, Evans, et al., 2012).

Table 4.12 Qualitative Informal Caregiver Post-Hospitalization Interview “Yes” or “No” Questions with Exemplars (N=23)

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes*</th>
<th>No*</th>
<th>Exemplar</th>
</tr>
</thead>
<tbody>
<tr>
<td>While (patient’s name) was in the hospital did you visit him/her?</td>
<td>23</td>
<td>0</td>
<td>“Visited daily at various times.”</td>
</tr>
<tr>
<td>Now I am going to ask you if you saw any of the following symptoms or changes:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory concentration</td>
<td>13 (4)</td>
<td>9</td>
<td>“Yeah, the one time when the nurse went and woke him he didn’t know where he was.”</td>
</tr>
<tr>
<td>Focusing attention</td>
<td>12 (4)</td>
<td>11</td>
<td>“It seems like she couldn’t keep her thoughts on anything. She would look away and lose you.”</td>
</tr>
<tr>
<td>Disorganized, incoherent, rambling, unclear or illogical speech</td>
<td>6 (2)</td>
<td>17</td>
<td>“I didn’t even know what he was saying sometimes.”</td>
</tr>
<tr>
<td>Excessive drowsiness or sleepiness</td>
<td>7 (3)</td>
<td>16</td>
<td>“That’s what I meant by being dull some of the times.”</td>
</tr>
<tr>
<td>Not knowing where he/she was or the time of day</td>
<td>8 (2)</td>
<td>15</td>
<td>“When I got there he wasn’t sure where he was. He asked me if he was in the hospital. He asked me again to make sure.”</td>
</tr>
<tr>
<td>Seeing or hearing things not present</td>
<td>7 (2)</td>
<td>16</td>
<td>“Yes he would reach for things going across the bed that weren’t there.”</td>
</tr>
<tr>
<td>Wandering, combativeness, or yelling out</td>
<td>3 (1)</td>
<td>20</td>
<td>“Yes. There were times when he became really agitated.”</td>
</tr>
<tr>
<td>Did anyone talk to you about the problems, symptoms or confusion during the hospitalization?</td>
<td>2 (1)</td>
<td>11</td>
<td>“Yes, they were trying to get an understanding of how much he knew before.”</td>
</tr>
<tr>
<td>Was there any information about your relative’s thinking and memory that YOU had that you think would have been helpful for the hospital staff to know?</td>
<td>6 (2)</td>
<td>17</td>
<td>“Yes, that she was not acting normally.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“The hospital staff didn’t know his baseline.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>“... The nurses really didn’t have time to talk to anyone like me.”</td>
</tr>
<tr>
<td>Did anyone on the hospital staff talk to you about managing problems, symptoms, or confusion</td>
<td>1 (0)</td>
<td>17</td>
<td>“Not really.”</td>
</tr>
</tbody>
</table>
that we have talked about at home?

| Have you heard the phrase acute confusion before? | 7 (2) | 16 | “Yes that means they have trouble focusing like she does.” |
| Have you heard the term delirium before? | 17 (4) | 6 | “Yes. Delirium means not making any sense of reality or not in touch with reality. Just totally out of touch.” |

*Not all Informal Caregivers Answered Every Question; Numbers in parentheses represent ‘Yes’ answered to patients rated as having delirium by research assistants using the Confusion Assessment Method (CAM)*

**Qualitative Thematic Analysis.** Qualitative themes were determined using previously described methods by Morgan and Krueger (1998) and were derived from data using the following questions asked to informal caregivers using the semi-structured interview guide (Appendix A):

Tell me about (patient’s name) thinking and memory while they were in the hospital.

How do you feel about how the hospital staff managed any symptoms or problems we have just talked about?

What did the hospital staff do that you thought was helpful to manage the symptoms, problems, or confusion we have talked about during the hospitalization?

What could the hospital staff done differently to manage the symptoms, problems, or confusion we have talked about during the hospitalization?

Did anyone talk to you about the problems, symptoms or confusion during the hospitalization?

How is (patient’s name) doing since hospital discharge?

Any other information you would like to share?

Two investigators (A.M.Y & D.M.F) separately read the line-by-line items and developed codes. The codes were then brought to several meetings and developed into higher order themes until thematic saturation was reached. Qualitative themes included: “Communication”; “Transitions”; and “Returning to Normal or Not”. Exemplars from the qualitative themes are followed by whether the
patient was rated as delirium positive or negative per the Confusion Assessment Method as rated by a trained research assistant within 24 to 48 hours of hospital admission.

Transitions. Transitions were a temporal theme throughout the data in terms of the transition in and out of the acute care facility, but also the transition in thinking and memory of the individual during the course of the hospitalization. With regards to transitions representing a change in location or place, informal caregivers identified multiple transitions in location, with patients discharged to a different facility or being readmitted to the same or a different acute care facility.

“He was discharged Friday. The home called Sunday and said he has a problem with his arms and he had an infection there. Tuesday he was admitted to the wound center. Then I got a phone call today and he is back at Central general.” (Delirium positive per Confusion Assessment Method)

Informal caregivers identified the difficulty of transitions for patients and for themselves, as exemplified by the following:

“... I don’t know how she got to Hillcrest, but I know it was traumatic for her. I explained to her what was going on, that she was going to rehab from the hospital and that she needed exercise. She was okay with that. She knew I wasn’t going to the there when she left, or go with her, but I would be there at rehab to meet her because they said they were picking her up at 6 p.m., so I thought I would meet them over at Hillcrest. I know I should have stayed and followed them over. She said they ripped her IV’s out and threw her on the litter. I knew part of it was true because I was there when they brought her on the litter and they just dumped her off. They ignored her... She was obviously scared and they didn’t even talk to her and tell her what was going on. They just picked her up and dumped her off.” (Delirium positive per Confusion Assessment Method)
Informal caregivers identified a key feature of delirium, fluctuation in thinking and memory, as a transition between thinking clearly and not thinking clearly as exemplified by the following:

“From what I saw on the day I was there she was fine. This was in the morning; seemed to be thinking clear. After she ate lunch and took a nap and fell asleep. When she woke she wasn’t the same woman. She was confused. She didn’t know where she was at. Very confused, acted confused, looked confused. Didn’t go away by the time we left.” (Delirium negative per Confusion Assessment Method)

Another account of fluctuation by an informal caregiver:

“The first couple of days she was in she seemed okay. Sunday and Monday she was real clear. Monday she had her surgery and when she woke up from surgery she was very clear. On Tuesday and Wednesday she was rather disoriented. By Thursday she was getting better and on Friday she was okay and went back to The Landings at Crestmont.” (Delirium negative per Confusion Assessment Method)

Transitions were not only seen as a change in location, but also as an adjustment period. Based on the data, it appears as if informal caregivers understand that there may be a transitional period in which the individual with dementia may experience delirium, but that the delirium will resolve over time and that they should eventually return to baseline.

“Right now she is at Hillcrest for rehab and she is sleeping a lot. She is going downhill. I was just talking to the nurses over there this morning about this. I was talking to the staff this morning about my mom. I don’t know if it is the infection or the medications she is getting, but she is not getting better. I was waiting all week for this transition time, but I think it’s been long enough. She has been there a week. I think she would have been able to adjust to the new place by now. She is
more alert in the morning. They said she has been sleeping well. I try to see her in the morning when she is more alert. Sometimes she can’t even make it through therapy. She is just not herself. She even notices it; she says she is getting more lazy . . .” (Delirium positive per Confusion Assessment Method)

Another informal caregiver states a similar view:

“She’s been terrible. She was released Monday after lunch and we went back to the nursing home . . . She has gotten progressively worse since hospitalization. She is more confused. No recognition at all. My brother saw her over the weekend for the first time in awhile and he just said to me he didn’t realize things were this bad. She can’t remember anything. We had to keep telling her the same things again and again . . . She has never been this bad. I was expecting her to be worse after the hospitalization. You know more confused for a day or two after the hospital stay, but nothing like this. She’s just so confused . . .” (Delirium positive per Confusion Assessment Method)

The theme of transitions was evident in the qualitative data appearing as a change in thinking in memory, a change in location or facility, and as a period for adjustment.

Communication. The theme of communication regarding delirium between informal and formal caregivers was prominent throughout the data. Overall, the qualitative data suggests that there is a significant lack of communication in the acute care setting, not only regarding delirium, but also in basic communication and in identifying the plan of care. This is exemplified by the following quotes from informal caregivers:

“Luckily I was there while the nurse came in to do his temperature, pulse, blood pressure, and oxygen. I did all I could do just to get her to say hello to me. Another nurse barely gave me the time of day.” (Delirium positive per Confusion Assessment Method)
Similar experiences by different informal caregivers, across both sites:

“I know they are short staffed, but they could ask questions or at least tell us what the plan is for that day or what is going on.”

“No not really. They were interested in their charts, taking vital signs, giving medications. I was there all day, everyday. I watched the nurses; they were always busy in the hallways or nurses station. They never stopped moving. These nurses really didn’t have the time to talk to anyone like me.” (Delirium negative per Confusion Assessment Method)

In contrast to a lack a communication, some informal caregivers had positive experiences regarding formal healthcare staff, as exampled by the following:

“. . . They were more engaged talking to me and my sister. They tried to learn our names and called us by name. They introduced themselves and even went so far as to shake our hands. I can’t remember a nurse wanting to shake my hand while my mom was in the hospital.” (Delirium positive per Confusion Assessment Method)

Experiences depicted above were atypical. The majority of informal caregivers interview qualitatively expressed a breakdown in communication regarding their loved ones care, but this does demonstrate the variability across sites of care and individual healthcare providers. The theme of communication was prominent with most informal caregivers expressing a desire to be a more active participant in the care of the hospitalized individual with dementia.
Returning to Normal or Not. The qualitative theme of Returning to Normal or Not was evident in the data. Informal caregivers expressed an understanding of what was normal for the individual, despite having underlying dementia as evidenced by the following:

“She was more confused than I have ever seen her in the hospital. Normally when she is in the hospital it’s the usual wanting to get out, asking when she is going home, those types of things. This time, there was this one afternoon, when I walked in and she was pushing her intravenous line pole around, saying ‘I gotta get back to Bethlehem. I can’t afford this. They are stealing my money.’ I explained to her that her insurance would be paying and she just collapsed. She was exhausted. She had herself worked up in a tizzy. She was very anxious and agitated. I have never seen her where she didn’t know she was in Altoona at the hospital. That has never happened before. This time she didn’t even know where she was. You have to understand she moved around a lot recently, so I understand how she might be confused, but never like this before. The way she’s been acting this is not my mom. My mother has never been like the way she’s been acting now . . .” (Delirium positive per Confusion Assessment Method)

Informal caregivers also expressed an understanding of what was a normal, or expected change in thinking and memory, during the hospitalization, and what was not; drawing from their past experiences. They were also able to identify potential causes for a change from normal.

“Well she was confused, which she normally is. I would say that she seemed to be very dull at times. It may have had to do with her pain medications. I know she had a lot of them at times. One of the things I noticed was that this time she didn’t have the hallucinations she had before when she was in the hospital. She stayed more lucid this time. She was still confused, but it wasn’t as bad as prior hospitalizations. She has been in the hospital 3 or 4 times in the past year or so.” (Delirium positive per Confusion Assessment Method)
As a component of the telephone interview, informal caregivers were asked how the person with dementia was doing since hospital discharge. The data indicate that some persons returned to normal, while other continued to experience cognitive and physical decline after hospitalization.

“He seems a little better. He knows who I am. The only thing is he calls me his mother. I told him I was not his mother I was Viola. After that he stopped calling me his mother.” (Delirium negative per Confusion Assessment Method)

Overall the qualitative data indicate that more persons were considered to have declined (N=10) since hospitalization.

“I noticed yesterday at the rehab facility that he didn’t even notice who I was. I walked into the room and he just stared at me, his eye contact was off. He would look at me like he knew me, but he wasn’t able to focus like he normally does. Normally he does have issues with his dementia. It has progressed fairly far, but he normally attempts to make conversation with you. I would walk into a room before and he would ask me how I was doing or what was going on at home. Yesterday his eye contact wasn’t good . . . I plan on visiting him this evening and seeing how he is doing, but everyday since the accident, he fell and broke his leg, he seems to be getting worse. He won’t even attempt conversations with you now which is a big change.” (Delirium negative per Confusion Assessment Method)

Informal caregivers, as depicted by the qualitative data, are able to recognize and establish a sense of normalcy in persons with pre-existing dementia. There is also a sense of what is expected with an acute illness and hospitalization and what is beyond the normal consequences of this experience.
Chapter 5

Discussion

Overview of Significant Findings

Despite overall poor agreement between informal caregiver and research assistant ratings of delirium found in this study, it has several important and surprising results. First this descriptive, exploratory study adds to the body of knowledge that informal caregivers can detect and report symptoms of delirium in persons with pre-existing dementia (Steis, Evans, et al., 2012). Most importantly, informal caregivers detected the symptoms of acute change and inattention in all cases of full delirium in this study, both of which are considered central features of delirium (Huang et al., 2012), with support from descriptive, qualitative data as well. Agreement between informal caregiver and research assistant ratings improved when cases of full and subsyndromal delirium were combined. Also, informal caregivers were less likely to recognize delirium in persons with more pre-existing cognitive impairment or advanced stages of dementia, which is consistent with formal healthcare provider detection and recognition of delirium (Ryan et al., 2013). Lastly, this study found a lack of communication between informal caregivers and formal healthcare providers in providing delirium care to persons with dementia in the acute care setting and across transitions of care.

Informal Caregiver Detection and Recognition of Delirium in Persons with Pre-Existing Dementia

Delirium is poorly detected and recognized by formal healthcare providers, particularly in persons with pre-existing dementia, despite the significant personal and economic consequences (Fong, et al., 2012). Informal caregivers have demonstrated that they are able to detect and recognize symptoms associated with multiple conditions and syndromes, including dementia (Hayes, et al., 2010; Hilton, et al., 2009). Extending this to detection and recognition and delirium as a means to improve outcomes is novel, yet needed. The following discussion will speak to the quantitative and qualitative findings regarding
informal caregiver detection and recognition of delirium in persons with pre-existing dementia, including a
discussion of detection and recognition of the following: full delirium, subsyndromal delirium, and
individual features of delirium. In addition, patient and informal caregiver factors and their relationship to
detection and recognition of delirium in persons with pre-existing dementia will be discussed.

**Detection and recognition of full delirium.** The Confusion Assessment Method (CAM) specifies
that to be positive for delirium is to have both acute onset and fluctuating course, as well as inattention,
and either disorganized thinking or altered level of consciousness (Inouye, et al., 1990b). Applying
validated CAM criteria to the Family Confusion Assessment Method (FAM-CAM), there was agreement
between informal caregivers and trained research assistants on one full case of delirium in this study
(Kappa=0.07). In addition to the one case where both the informal caregiver and the trained research
assistant detected full delirium, informal caregivers rated a total of eight patients as having full delirium,
while trained research assistants found a total of five cases of full delirium.

The Confusion Assessment Method (CAM) is considered the most valid and reliable tool to detect
delirium in persons with pre-existing dementia, although it was not developed specifically for this use
(Morandi, et al., 2012); an extension of this tool is the Family Confusion Assessment Method (FAM-CAM).
Convergent validity of this tool was recently undertaken by Steis et al. (2012) with results demonstrating
significant agreement between informal caregivers and trained research assistants on ratings of full
delirium (Kappa=0.85). This differs from findings of this study (Kappa=0.07 versus 0.85). The Steis et al.
study sample also included informal caregivers of persons with pre-existing dementia and their informal
caregivers, but was conducted within a home health service, not in acute care. Administration of the tool
in this study was distinctly different. In the Steis et al. study, the FAM-CAM tool was self-administered by
informal caregivers after formal training by research staff. Informal caregivers could also access research
staff on an as-needed basis to answer questions regarding tool use.
Results from this study also build upon a current body of literature aiming at the best way to ask questions regarding features of delirium to obtain valid and reliable answers. Huang et al. (2012) used the method of expert consensus, with seven interdisciplinary panelists, to determine important diagnostic features of delirium. Results from this study determined that indicators such as patient interview, administration of cognitive assessments, and observations were important for determination of delirium; indicating the need to incorporate multiple assessments for delirium detection and recognition (Huang, et al., 2012). In addition, recent research by Yang et al. (2013) has focused on identifying specific, direct questions to be incorporated into clinical practice aimed at determining the presence of delirium symptoms.

Detection and recognition of subsyndromal delirium. Agreement between informal caregivers and trained research assistants with regards to ratings of subsyndromal delirium was less than chance (Kappa=-0.02); however, agreement for combined cases of full and subsyndromal was slightly better (Kappa=0.31). Subsyndromal delirium is poorly defined and measured currently (Cole, 2013; Zuliani et al., 2013). In this study, subsyndromal delirium is defined having at least two features of delirium per the CAM, but not meeting full delirium criteria. This definition is the most commonly used definition for subsyndromal delirium (Cole, 2013).

Subsyndromal delirium, like full delirium, is poorly detected and recognized, yet has significant outcomes in older adults (Cole, Ciampi, Belzile, & Dubuc-Sarrasin, 2012; DeCrane, Culp, & Wakefield, 2012; Trzepacz et al., 2012). Individuals with subsyndromal delirium experience increased risks of mortality and morbidity, long lengths of stay in acute and post-acute care, and higher rates of lasting functional and cognitive decline (Cole, et al., 2003; Marcantonio et al., 2005; Voyer, Richard, Doucet, & Carmichael, 2009). Development of subsyndromal delirium is more likely to occur in vulnerable individuals, including those at older ages and persons with greater baseline physical and cognitive...
dysfunction (Kiely et al., 2004; Zuliani, et al., 2013). A recent study by Zuliani et al. (2013) estimated the prevalence of subsyndromal delirium to be 37% of hospitalized adults over the age of 65 years.

The relationship between full and subsyndromal delirium, and its relationship to recovery and outcomes is just beginning to be fully explored. Cole et al. (2011) recently described risk factors and outcomes associated with subsyndromal delirium in long-term care, categorizing subsyndromal delirium according as having one or two features of delirium according to the Confusion Assessment Method. The more restrictive definition of subsyndromal delirium, having two or more features of delirium, was associated with poorer functional and cognitive outcomes at six months (Cole, et al., 2011). Some research has been done in describing subsyndromal delirium as a precursor to full delirium, or as a potential marker for the development of full delirium (J. G. Franco, Trzepacz, Mejia, & Ochoa, 2009). Meagher et al. (2012) investigated patterns of full and subsyndromal delirium, as well as persistence or resolution of symptoms over a six-week period, in patients with a cancer diagnosis admitted to a palliative care unit. Prevalence of subsyndromal delirium in this population was 27%. Results from this investigation indicate the persistence of subsyndromal delirium, as well as the conversion of subsyndromal delirium into full delirium (Meagher, et al., 2012). Results from this study indicate that inattention is also a core feature of subsyndromal delirium. Subsyndromal delirium was characterized by having similar, but less severe features as full delirium as measured by the Delirium Rating Severity Scale-Revised-98 (Meagher, et al., 2012).

Considering that this study only included baseline measures of delirium from both the informal caregiver and trained research assistant, the relationship between full and subsyndromal delirium has not been explored here. It is not known if individuals who display subsyndromal delirium upon admission proceed to develop full delirium or recover. More research is needed to determine when subsyndromal delirium is more likely to resolve or to develop into full delirium (Cole, 2013), including exploration of individual, informal and formal caregiver, and environmental factors across settings of care. It is also not
know whether the outcomes are improved if subsyndromal delirium is detected and recognized earlier, preventing full delirium or if there is no impact on development of delirium. Subsyndromal delirium is common and has personal and economic implications comparable to delirium; there is important practice and research implications in this area, including elucidating distinctions between full and subsyndromal delirium.

Detection and recognition of individual delirium features. According to Confusion Assessment Method criteria, the main features of delirium include: acute onset, fluctuating course, inattention, disorganized thinking and altered level of consciousness (Inouye, et al., 1990b). The CAM operationalizes the definition of delirium according to the American Psychological Association’s Diagnostic and Statistical Manual of Mental Disorders, Version III (DSM-III) and the International Disease Classification, Version 10 (ICD-10) (Yang, et al., 2013). More recent DMS-IV criteria add the additional criteria of having a medical cause for delirium (American Psychiatric Association, 2013).

Informal caregivers and research assistants in this study had 100% agreement regarding the features of acute onset and inattention in cases of full delirium; indicating that informal caregivers are recognizing these changes. With regards to additional feature agreement on full cases of delirium, there was little consistency between informal caregiver and research assistant ratings. Using results from the Kappa analyses, acute onset has a 100% sensitivity rating (few false negatives), while disorganized thinking has a specificity of over 85% (few false positives).

Drawing upon these findings, it may be critical to assess for the features of acute onset and inattention to detect and recognize delirium in persons with pre-existing dementia. Acute onset can be determined based on change from baseline or previous shifts in acute care. Inattention can be readily assessed at the beside in a clinical setting. Several tools to assess for inattention at the bedside include: counting the number of times an individual claps their hands; asking a patient to state the days of the
week or months of the year backwards; naming the colors in a rainbow; or performing digit span forwards or backwards (Kolanowski et al., 2012). In addition, recent research has focused on the use of technology to objectively assess inattention in persons with pre-existing dementia (Brown, Fordyce, Zaghdani, Starr, & MacLullich, 2011).

The Family Confusion Assessment Method also asked informal caregivers in this study to rate their recognition of the following delirium symptoms: disorientation, hallucinations, and inappropriate behaviors. Addition of the feature of disorientation slightly improved agreement between informal caregivers and research assistants, but this was still modest agreement at best. Disorientation is also a key feature of dementia, so with a population including dementia and delirium, these results must be interpreted with caution.

Currently, the features, and associated tool, best able to identify delirium in persons with pre-existing dementia are those of the Confusion Assessment Method (Morandi, et al., 2012), but there is no ideal tool for the detection and recognition of DSD. Research by Thomas et al. (2012) suggests that the addition of the feature of psychomotor alteration to current CAM criteria can help to detect delirium in persons with pre-existing dementia according to ICD-10 criteria. Additional evidence suggests that the feature of consciousness may also be an important indicator of delirium, particularly in persons with dementia (Eeles, Pandy, & Ray, 2013). Research also indicates the importance of inattention in identification of delirium (Meagher, et al., 2012). These results indicate that the importance of distinct delirium features remains cloudy. Identification of delirium in persons with pre-existing dementia is still in its infancy; more work needs to be done in this area to identify critical features to improve recognition and detection by both informal caregivers and formal healthcare providers.

**Factors impacting detection, recognition, and reporting of delirium.** Detection, recognition, and reporting of delirium may be impacted by characteristics of the individual. Formal healthcare providers
are less likely to recognize delirium, particularly in persons with pre-existing dementia (Fick, Hodo, et al., 2007; Inouye, et al., 2001). Individual characteristics that lead to poorer detection and recognition of delirium include the following: higher functional and cognitive impairment, multiple comorbidities, and increased age (Inouye, 2006b). In addition, the hypoactive subtype of delirium is less likely to be recognized by formal healthcare providers (Steis & Fick, 2012).

The impact of patient factors on informal caregiver detection, recognition, and reporting of delirium was examined in this study, drawing from research surrounding formal healthcare provider detection and recognition of delirium. Results indicate that informal caregivers were less likely to report delirium symptoms in persons with pre-existing dementia if they had more severe delirium as measured by the Delirium Rating Severity Scale-Revised-98 (DRS-R-98), and the hypoactive form of delirium. These results are surprising. Informal caregivers have an intimate knowledge of the patient with dementia and it was expected that they would be able to detect and recognize symptoms of delirium in spite of higher levels of delirium impairment and that they would be able to detect hypoactive delirium more readily. It may be that in later stages of dementia, these delirium symptoms may not be as important for the detection and recognition of delirium; considering that the sample in this study was moderately impaired. This has significant implications for personal and economic burden. Individuals with higher levels of pre-existing impairment and those with hypoactive delirium are known to experience more lasting and profound deficits (Fong, et al., 2012).

In addition to patient factors, informal caregiver factors were taken into account in this study. This is a new area of inquiry; so informal caregiver factors important in detection and recognition of delirium were taken from the literature surrounding informal caregiver detection and recognition of dementia and Alzheimer’s disease. Important factors explored were relationship and living arrangement between the patient and informal caregiver, education level of the informal caregiver, and their prior knowledge of
acute confusion or delirium. None of these informal caregiver characteristics were found to statistically impact the detection and recognition of delirium in this sample, possibly due to the small sample size.

Despite this, interesting and surprising results were found when Informal caregivers were asked regarding their knowledge of the phrase acute confusion or the term delirium. A total of seven informal caregivers were familiar with the phrase acute confusion and 17 informal caregivers stated they were familiar with delirium. Definitions for both acute confusion and delirium, provided by informal caregivers, included symptoms indicative of delirium, such as difficulty focusing attention, fluctuation (e.g., “comes and goes”), disorganized thinking (e.g., “Just totally out of touch”; “. . . talking mumbo jumbo”), and hallucinations. Several informal caregivers also defined delirium as dementia or Alzheimer’s disease; indicating that informal caregivers may need education regarding delirium in persons with pre-existing dementia. Others referred to hearing the term delirious, but not delirium; illustrating a potential problem with health literacy. There was also a negative stigma associated with delirium depicted by informal caregivers.

In summary, informal caregivers are able to detect and recognize critical features (e.g., acute change and inattention) in hospitalized older adults with pre-existing dementia. Patient characteristics impacting detection and recognition of delirium in persons with pre-existing dementia are similar across informal and formal care providers. More attention needs to be given to the understanding of delirium by informal caregivers to promote prompt detection and recognition in this critically vulnerable population.

**Partnerships between Informal Caregivers and Formal Healthcare Providers.**

Improvement in care, particularly in vulnerable populations such as those as with pre-existing dementia and individuals at high risk for delirium, results in better outcomes and lower cost of overall care (Burke & Coleman, 2013). Informal caregivers are critical team members to improving care and need to be included as such (Coleman, 2011). Results from this study indicate that informal caregivers
are not being utilized to their fullest extent with regards to delirium detection, recognition, and reporting of symptoms in acute care and post-acute care.

Informal caregivers in this study expressed a need for increased communication regarding the care plan and outcomes for the patient with dementia. In general informal caregivers stated that “. . . they had no idea what was going on.” All informal caregivers in this study visited the acute care facility at least once during the hospitalization, with most stating that they visited daily. That being said, informal caregivers were asked if any formal healthcare provider asked them about problems or symptoms of confusion, only two (out of 23) informal caregivers were able to positively respond that they their observations were asked. Despite this, qualitative evidence from this study indicated informal caregivers were aware of symptoms associated with delirium. At least 10 informal caregivers reported unresolved or worsening symptoms of delirium after acute care discharge.

The need for increased communication and incorporation of informal caregivers as a critical team member continued across transitions of care. It is well documented that delirium also continues across settings of care (Fong, Jones, et al., 2009; Kiely et al., 2003). Only one informal caregiver in this study reported information being given to them regarding delirium after an acute care hospitalization. Although informal caregivers were not directly asked about communication regarding delirium in the post-acute care setting, many expressed a lack of communication during these transitions of care.

Based on informal caregiver reports, at least two (5.26%) of the older adults with pre-existing dementia were re-admitted to an acute care setting within seven days of discharge. Research indicates that individuals with delirium superimposed on dementia are twice as costly as individuals with dementia or delirium alone (Fick, et al., 2005). In addition to overall healthcare costs of delirium, informal caregivers report delirium to be a distressing event in acute and post-acute care settings. Informal caregivers commented on the physical transition from one facility to another as being distressing and as an opportunity to improve communication.
Study Limitations and Strengths

Results from this study must be interpreted understanding the following limitations. First and foremost is a limitation of the instruments used. The Family Confusion Assessment Method (FAM-CAM) tool has not been validated for use in this setting. To date, only one validation study using this tool has been conducted. The population in that study was persons with pre-existing dementia, but in the home-care setting. Given the difference in results in that initial validation study, and the study presented here, this is a significant limitation. In the quantitative data the delirium feature of fluctuation had relatively low agreement between researcher and informal caregiver (Specificity equal to 61.54%, sensitivity equal to 47.06%, and Kappa equal to 0.08), yet the qualitative data indicates that informal caregivers recognized the fluctuating course of delirium. There are several potential explanations for this discrepancy. The FAM-CAM tool may not be effective in eliciting this information from informal caregivers. In addition, delivery of the FAM-CAM instrument in the parent study (END-DSD) asked informal caregivers to assess for the presence of delirium symptoms over a 14-day period, not for the presence of symptoms at that current moment in time. This is also a significant limitation. A final limitation with regards to the FAM-CAM tool and delivery was the timing and method. Informal caregivers and patients were enrolled within 48 hours of hospitalization. Ideally this would have been done within 24 hours. Also the tool may have been administered in different ways either in-person or over the telephone.

There are additional limitations surrounding the sample. Although this was an exploratory study, it included a relatively small sample size. Ideally, in this study, we were aiming for a sample size of 50 patient and informal caregiver dyads to improve the precision of Cohen’s kappa (Viera & Garrett, 2005). The limited sample size not only impacts kappa, but also the associated precision of the confidence interval (Tractenberg, Yumoto, Jin, & Morris, 2010). In addition, there was a significant amount of attrition. A total of 15 informal caregivers did not complete the post-hospitalized telephone interview. Not only did this
impact the qualitative data collected, but also data regarding their relationship to the patient, living arrangement, familiarity of acute confusion and delirium, and education level was not obtained. Attrition of informal caregivers in this exploratory study is significant because the informal caregivers lost may have been significantly different than those who did participate in the post-hospitalization telephone interview (Gustavson, von Soest, Karevold, & Roysamb, 2012). Research done regarding attrition of informal caregivers of persons with dementia suggest that male caregivers, adult child living with the person with dementia, and those who have high levels of burden are more likely to be lost to follow-up (Coley et al., 2008). Although not a measure of this study, anecdotally, few post-hospitalization telephone interviews were conducted with male informal caregivers. Also the small sample size prevented validation of the logistic regression model using cross-validation. A separate validation study of the model was not within the scope of this project.

In addition to the relatively small sample size, the characteristics of the sample did not fit larger estimates. The point prevalence of full delirium in this study was 16%, which is comparatively low to estimates of up to 53% of hospitalized older adults without dementia and 89% of hospitalized older adults with dementia (Fick, et al., 2002; Ryan, et al., 2013; Teodorczuk, Reynish, & Milisen, 2012). Given this information, the point prevalence of the only other validation study of the FAM-CAM tool was even lower at 13% (Steis, Evans, et al., 2012). The low prevalence of delirium in this study, and the Steis et al. (2012) study, may have potentially impacted the significant differences found in agreement.

Finally, the generalizability of this study must be considered. The population of interest was persons over the age of 65, with pre-existing dementia. This is a specific population. Generalization of results to other populations at high risk for delirium (i.e., persons with advanced cancer) must be done so with caution. Also, this study was conducted at only two sites in Central Pennsylvania and all patients were Caucasian. This has impact for generalizability beyond the geographic area.
Despite these caveats, this study has several strengths, including the fact that it was conducted within an ongoing, multi-site, cluster-randomized controlled clinical trial: Early Nurse Detection of Delirium Superimposed on Dementia (END-DSD). Use of data collected within the parent study, END-DSD, allowed for increased validity and reliability of instrument use, as well as, measurement of dementia and delirium. An additional strength of this study was the use of a researcher-developed post-hospitalization telephone interview form. This semi-structured interview guide allowed for systematic collection of qualitative data. The collection of both quantitative and qualitative data is a significant strength, especially so since the qualitative data collected supports the quantitative data. A final significant strength of this study was it’s descriptive, exploratory nature. The design of this study fit the current state of the science in this area and allowed for identification of future areas to explore.

**Implications and Recommendations for Future Research and Practice**

Informal caregivers have been used to improve delirium detection, recognition, and management in the acute care setting in prior studies, but to date this research has focused on the patient population of individuals with advanced cancer (Bruera, et al., 2009; Gagnon, et al., 2010; Gagnon, et al., 2002). Recent research has just begun to expand this work to older adults with and without pre-existing dementia (D. Rosenbloom-Brunton, E. Henneman, & S. Inouye, 2010a; Steis, Evans, et al., 2012). Informal caregivers can detect and recognize symptoms of delirium in persons with pre-existing dementia, particularly acute change and inattention. Results from this study support this assertion and have important considerations for future research and practice.

Future research on informal caregiver detection, recognition, and reporting of symptoms of delirium in persons with pre-existing dementia needs to begin with a larger study to extend and further develop the results found in this study. A larger study is necessary to assess a range of symptoms, patient characteristics, and informal caregiver characteristics most important for informal caregivers to
detect and recognize delirium. It would be ideal to conduct this type of study in a population with a great number of cases of delirium. Consideration of differences between full and subsyndromal delirium must also be taken into account. Supplemental work needs to be done to extend current research investigating assessment methods and questions best suited to determine presence of delirium symptoms (Huang, et al., 2012; Yang, et al., 2013) and tailor questions specific to informal caregivers of persons with pre-existing dementia, with attention to differences in settings of care (i.e., acute care, post-acute care, long-term care, home health, etc.).

To date the FAM-CAM tool is the only instrument to measure detection and recognition of delirium by informal caregivers. Further validation of this tool needs to be undertaken, specific to persons with dementia in the acute care setting. In addition, incorporation of current research, indicating the potential importance of additional delirium features, such as psychomotor alterations, should be included in additional validation of the FAM-CAM. Incorporating the FAM-CAM, or another instrument, within the electronic medical record should also be initiated. A larger study would enhance the generalizability of the findings present here, considering the relative small and homogenous sample. A larger sample might also have more statistically significant findings and consideration given to both patient and informal caregiver characteristics impacting detection and recognition of delirium. Given the significant of the qualitative findings within this study, recommendations for future research would include continuing to collect qualitative data.

Delirium in persons with dementia has lasting complications (Fong, et al., 2012; Vasilevskis & Ely, 2012) (Field & Wall, 2013) and occurs across transitions of care. Informal caregivers of this vulnerable population were not included as members of the healthcare team in this study, yet to best manage complications and to lessen the financial burden on the healthcare system they should be integral components to improving care. Several models, such as The Advance Practice Nurse Transitional Care
Model and the Care Transitions Intervention, have demonstrated improved outcomes in vulnerable populations (Burke & Coleman, 2013; Naylor, et al., 2007), but should be extended to persons with delirium and with delirium superimposed on dementia.

**Summary: Final Conclusions**

This exploratory, descriptive study aimed to begin to fill a critical gap in further understanding informal caregiver detection, recognition, and reporting of symptoms of delirium in persons with pre-existing dementia. Quantitative and qualitative data from this study suggest informal caregivers can aide in recognition and detection of delirium symptoms in acute care. In addition it supported the need for increased communication between formal healthcare providers and informal caregivers, giving support that informal caregivers are a core component of the transdisciplinary healthcare team, particularly in vulnerable populations. This research has begun to lay a foundation in an area that continues to need more exploration with regards to research and improvement in clinical practice. Doing so will not only improve outcomes for older adults with dementia and delirium and informal caregivers, but also lessen the economic burden on an overstretched healthcare system in the United States.
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Appendix A

Informal Caregiver Post-Hospitalization Follow-Up

Interview Guide

Study ID:            Researcher Initials:            Date:        Time:        Hospital ID:

Hello. My name is (Andrea Yevchak) and I am calling from The Pennsylvania State University School of Nursing and the END-DSD Project. (Patient’s Name) was recently hospitalized and participated in our study during their hospitalization at (Mount Nittany Medical Center or Altoona Regional Medical Center). As part of the study some informal caregivers or family members receive a follow-up telephone interview. The interview will take approximately 20 to 30 minutes. I was wondering if this was a good time to complete the interview with you.

If not, is there another time I could call you back? What time of day is best to reach you?

Participant Death:

If patient has died since hospitalization, give condolences to informal caregiver.

I am sorry for the loss of your (mother, father, husband, wife, etc.). Is there anything that we can do at this time for you? Thank you for allowing your (mother, father, husband, wife, etc.) to participate in our study. It is greatly appreciated.

End interview.

1. While (patient’s name) was in the hospital did you visit him/her? (Probes: How often? At what times of the day?)

2. Tell me about (patient’s name) thinking and memory while they were in the hospital. (Probes: Were they confused while in the hospital? Were they mixed-up, not thinking straight, talking inappropriately?)

3. Now I am going to ask if you saw any of the following symptoms or changes (Probe: Different from baseline, usual status or being) while you were visiting (patient’s name) at any time during the hospitalization?

(Probes for All Items: If yes, can you describe the situation or experience? Can you tell me more about that? What was it like for you? Did these symptoms or problems there all the time, or did they tend to come and go? Do you think these symptoms of problems have been getting better, worse, or staying about the same?)

☐ Problems with memory or concentration, such as being less attentive, appearing confused or disoriented (i.e., not knowing where he/she was), behaving inappropriately, or sleeping all day?

☐ Problems focusing attention, for example, being easily distracted or having trouble keeping track of what you were saying?
Problems with disorganized, incoherent, rambling, unclear or illogical speech?

Excessive drowsiness or sleepiness during the daytime?

Not knowing where he/she was or mixing-up the time of day, for example, mixing up days and nights?

Problems seeing or hearing things that were not present or mistaking something that he/she saw for something else?

Problems with wandering, yelling out, or being combative or agitated?

4. How do you feel about how the hospital staff managed any symptoms or problems we have just talked about? 
*(Probes: How did the physician or medical staff manage any confusion? How did the nursing staff manage the confusion?)*

5. What did the hospital staff do that you thought was helpful to manage the symptoms, problems, or confusion we have talked about during the hospitalization?

6. What could the hospital staff done differently to manage the symptoms, problems, or confusion we have talked about during the hospitalization?

7. Did anyone talk to you about the problems, symptoms or confusion during the hospitalization? *(Probes: Who? What did they ask? How often did they communicate with you? Were you asked questions about (patient’s name) behavior or symptoms at home or prior to the hospitalization or recent illness? Were you called at home if you were not present at the hospital?)*

8. Was there any information about your relative’s thinking and memory that YOU had that you think would have been helpful for the hospital staff to know? *(Probes: Is there information only you would know about your relative’s thinking and memory or mental status? Did you share this information with anyone? Who? When? Did anyone ask for the information? How was the information received?)*
9. Did anyone on the hospital staff talk to you about managing problems, symptoms, or confusion that we have talked about at home? (Probes: Who? When? Was there information provided at discharge you consider useful or valuable?)

10. How is (patient’s name) doing since hospital discharge? (Probes: Have they continued to have problems, symptoms, or confusion at home or in the nursing facility? Are they back to normal? When do you think they were back to being their normal routine? How are you managing any problems, symptoms, or confusion at home?)

11. Have you heard the phrase acute confusion before? (Probes: Can you tell me what you know about it? What does this phrase mean to you? Where have you heard it being used before? In what circumstances?)

12. Have you heard the term delirium before? (Probes: Can you tell me what you know about it? What does this phrase mean to you? Where have you heard it being used before? In what circumstances?)

Demographic Questions

13. What is your relationship to (patient’s name)?
   - Spouse
   - Son/Daughter
   - Son-in-Law/Daughter-in-Law
   - Brother/Sister
   - Brother-in-Law/Sister-in-Law
   - Friend
   - Other

14. Do you live with (patient’s name)?
   - Yes
   - No, if not, where do they live?

15. How many years of formal education have you received?
   - Did not Graduate High School
   - Graduated High School
Conclusion

1. Is there anything else you would like to tell me or share with me about (patient’s name) hospital stay or about how he/she is doing since?
Appendix B

PROXY SCREEN

Hello my name is ___________; we are doing a study to look at older people in the hospital at the ______________. Part of our study involves speaking with someone who can tell us about how (Patient Name) memory and health were prior to his/her admission to the hospital. Would you be willing to answer some questions?

1. Do you live with (Patient Name)?
   YES 1
   NO 2
   Skip to question 2

   1a. Have you known (patients name) at least 5 years?
       Go to Proxy interview
       YES 1
       NO 2
       Skip to question 5

2. Do you see (Patient Name) at least twice a week?
   YES 1
   NO 2
   Skip to question 3

   2a. Have you known the patient at least 5 years?
       Skip to question 4
       YES 1
       NO 2
       Skip to question 5

3. Do you spend at least four hours a week with (Patient Name)?
   YES 1
   NO 2
   Skip to question 5

   3a. Have you known the patient at least 5 years?
       Skip to question 5
       YES 1
       NO 2

4. Can you assess (Patient Name) memory and mental abilities?
   Go to Proxy interview
   YES 1
   NO 2

5. Do you know of anyone else (friend, relative, or nurse’s aide) who has known (Patient Name) for at least 5 years spoke with at least 4 hours per week and can tell us how (Patient Name) was before hospitalization?

   Name_______________________________________________________

   Phone number_______________________________________________
MODIFIED BLESSED DEMENTIA RATING SCALE (MBDRS)

Note: If unable to rate due to refusal or “don’t know” then please write this in the margin.

I. Check the box which best rates level of memory and performance during the past 6 months

<table>
<thead>
<tr>
<th>During the 6 months prior to hospitalization have you noticed any problem with (Patient name)’s ability…(REPEAT PROMPT FOR QUESTIONS 1-8)</th>
<th>0</th>
<th>0.5</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) To perform usual household tasks?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) To cope with small sums of money?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) To remember a short list of items, such as a shopping list?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) To find way about indoors, either in home or in other familiar locations?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5) To find way around familiar streets? (On foot or by car)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6) To grasp situations, or to recognize surroundings or people?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7) To recall recent events?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8) Tendency to dwell in the past?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 = No problem</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0.5 = Some problem (e.g. sometimes, partial)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1= Severe problem or inability</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

II. For each ADL below, choose which one currently (past 2 weeks/prior to this illness) describes the patient with dementia

<table>
<thead>
<tr>
<th>Eating</th>
<th>0</th>
<th>Feeds self without assistance.</th>
<th>1</th>
<th>Feeds self with minor assistance.</th>
<th>2</th>
<th>Feeds self with much assistance.</th>
<th>3</th>
<th>Has to be fed.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Dressing</th>
<th>0</th>
<th>Unaided.</th>
<th>1</th>
<th>Occasionally misplaces buttons, etc. Requires some help.</th>
<th>2</th>
<th>Wrong sequences, forgets items, requires much assistance.</th>
<th>3</th>
<th>Unable to dress.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Toilet</th>
<th>0</th>
<th>Cleans, cares for self at toilet.</th>
<th>1</th>
<th>Occasional incontinence, or needs to be reminded.</th>
<th>2</th>
<th>Frequent incontinence, or needs much assistance.</th>
<th>3</th>
<th>Little or no control.</th>
</tr>
</thead>
</table>

III. Total Score of Modified Blessed Dementia Scale (0-17) ____________ Score > 3 Consistent with dementia
### CDR Staging Summary

<table>
<thead>
<tr>
<th>Memory</th>
<th>Orientation</th>
<th>Judgment &amp; Problem Solving</th>
<th>Community Affairs</th>
<th>Home &amp; Hobbies</th>
<th>Personal Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No or slight memory loss; inconstant forgetfulness</td>
<td>Fully oriented</td>
<td>Solves everyday problems well; judgment good in relation to past performance</td>
<td>Independent function at usual level in job, shopping business &amp; financial affairs, volunteer &amp; social, group</td>
<td>Life at home; hobbies, intellectual interests well-maintained</td>
</tr>
<tr>
<td>0.5</td>
<td>Consistent slight forgetfulness; partial recollection of events “benign forgetfulness”</td>
<td>Fully oriented except for slight difficulty with time relationship</td>
<td>Slight impairment in solving problems, similarities, differences</td>
<td>Slight impairment in these activities</td>
<td>Life at home, hobbies, intellectual interests slightly impaired</td>
</tr>
<tr>
<td>1.0</td>
<td>Moderate memory loss; more marked for recent events; defect interferes with everyday activities</td>
<td>Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere</td>
<td>Moderate difficulty in handling problems, similarities, differences; social judgment usually maintained</td>
<td>Unable to function independently at these activities though may still be engaged in some; appears normal to casual inspection</td>
<td>Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned</td>
</tr>
<tr>
<td>2.0</td>
<td>Severe memory loss; only highly learned material retained; new material rapidly lost</td>
<td>Severe difficulty with time relationship; usually disoriented in time, often to place</td>
<td>Severe impaired in handling problems, similarities, differences; social judgment usually impaired</td>
<td>No pretense of independent function outside home. Appears well enough to be taken to functions outside family home</td>
<td>Only simple chores preserved, very restricted interests, poorly sustained</td>
</tr>
<tr>
<td>3.0</td>
<td>Severe memory loss; only fragments remain</td>
<td>Oriented to person only</td>
<td>Unable to make judgment or solve problems</td>
<td>No pretense of independent function outside home. Appears too ill to function outside family home</td>
<td>No significant function in home</td>
</tr>
</tbody>
</table>

**Profound 4.0**  Speech usually unintelligible or irrelevant; unable to follow simple instructions or comprehend commands occasionally recognized spouse or caregiver. Uses fingers more than utensils, require much
assistance or training. Able to walk a few steps with help; usually chair-bound; rarely out of home or 
residence; purposeless movements often present.

Terminal 5.0 No response or comprehension. No recognition. Needs to be fed, may have NG tube and/or swallowing 
difficulties. Total incontinence. Bedridden, unable to sit or stand, contractors.

0 = No dementia
0.5 = Uncertain/deferred diagnosis
1 = Mild dementia
2 = Moderate dementia
3 = Severe dementia
4 = Profound dementia
5 = Terminal dementia

Current Staging of Dementia Total _____________________________
CONFLUSION ASSESSMENT METHOD (CAM) WORKSHEET

<table>
<thead>
<tr>
<th>I. Acute Onset and Fluctuating Course</th>
<th>BOX 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Is there evidence of an acute mental status change from patient’s baseline?</td>
<td>NO</td>
</tr>
<tr>
<td>b. Did the (abnormal) behavior fluctuate during the day, that is, did it tend to come and go, or increase and decrease in severity?</td>
<td>NO</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>II. Inattention</th>
<th>BOX 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Did the patient have difficulty focusing attention, for example, being easily distractible or having difficulty keeping Track of what was being said?</td>
<td>NO</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>III. Disorganized Thinking</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a. 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?</td>
<td>NO</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IV. Level of Consciousness</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Overall, how would you rate the patients level of consciousness?</td>
<td></td>
</tr>
<tr>
<td>□ Alert (normal)</td>
<td></td>
</tr>
<tr>
<td>□ Vigilant (hyperalert)</td>
<td></td>
</tr>
<tr>
<td>□ Lethargic (drowsy, easily aroused)</td>
<td></td>
</tr>
<tr>
<td>□ Stuporous (difficult to arouse)</td>
<td></td>
</tr>
<tr>
<td>□ Comatose (unarousable)</td>
<td></td>
</tr>
</tbody>
</table>

Did any checks appear in the above box? | NO | YES |

Positive for delirium per above CAM? | 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. They have to have both items 1 and 2 present and either 3 or 4*

*If patient does not meet full criteria but 2 or more items are checked YES, mark YES for Subsyndromal Delirium.*

FAMILY CONFUSION ASSESSMENT METHOD (FAM-CAM)

In the past week (or before death), has (he/she) had any problems with (his/her) memory or concentration, such as being less attentive, appearing confused or disoriented (not knowing where he/she was), behaving inappropriately, or sleeping all day?

☐ Yes
☐ No
☐ Refused
☐ Don’t Know

Did (he/she) have difficulty focusing attention, for example, being easily distracted or having trouble keeping track of what you were saying?

☐ Yes
☐ No
☐ Refused
☐ Don’t Know

Was (his/her) speech disorganized, incoherent, rambling, unclear, or illogical?

☐ Yes
☐ No
☐ Refused
☐ Don’t Know

Did (he/she) seem excessively drowsy or sleepy during the daytime?

☐ Yes
☐ No
☐ Refused
☐ Don’t Know

Was (he/she) disoriented, for example, thinking (he/she) was somewhere other than where (he/she) was or misjudging the time of day?

☐ Yes
☐ No
☐ Refused
☐ Don’t Know

Did (he/she) seem to see or hear things, which weren't actually present, or seem to mistake what (he/she) saw or heard for something else?

☐ Yes
☐ No
☐ Refused
☐ Don’t Know

Did (he/she) behave inappropriately, such as wandering, yelling out, or being combative or agitated?

☐ Yes
☐ No
☐ Refused
☐ Don’t Know

Descriptive Information
Were these problems present all the time, or did they come and go from day to day?

- □ Come and go
- □ All the time
- □ Refused
- □ Don’t Know
- □ N/A

How long have you noticed these problems (in days)?

Overall, have these problems been getting better, worse, or staying the same in the past week?

- □ Better
- □ Worse
- □ About the same
- □ Other
- □ Don’t Know
- □ Refused

Other (please specify):
**DELIRIUM RATING SCALE-REVISED-98**

**DRS-R-98 SCORESHEET**

**TOTAL SCORE:**

<table>
<thead>
<tr>
<th>Severity Item</th>
<th>Item Score</th>
<th>Scoring Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short Term Memory</td>
<td>0 1 2 3</td>
<td>Refer to MMSE Recall</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0 = \text{Recalls 3/3 items}, 1 = \text{Recalls 2/3 items}, 2 = \text{Recalls 1/3} )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(3 = \text{Recalls 0/3 items} )</td>
</tr>
<tr>
<td>Long Term Memory</td>
<td>0 1 2 3</td>
<td>Refer to “Additional Assessment Questions used to assist in scoring”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0 = \text{Identifies 3/3 items (No significant long-term memory deficits)}, 1 = )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(\text{Identifies 2/3 items (Minor difficulty recalling details of long-term information)}, 2 = )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(\text{Identifies 1/3 items (Moderate difficulty recalling long-term information)}, 3 = )</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(\text{Identifies 0/3 items (Severe difficulty recalling long-term information)} )</td>
</tr>
<tr>
<td>Orientation</td>
<td>0 1 2 3</td>
<td>Refer to MMSE Orientation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0 = \text{Oriented to person, place and time}, 1 = \text{Disoriented to time (e.g., by more than 2 days or wrong month or wrong year)} ) OR</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(\text{Disoriented to place (e.g., name of building, city, state), but not both), 2 = \text{Disoriented to time and place}, 3 = \text{Disoriented to person} )</td>
</tr>
<tr>
<td>Attention</td>
<td>0 1 2 3</td>
<td>Refer to MMSE Attention and Calculation. Also consider DOW backwards and overall interview.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0 = \text{Scored 5 out of 5. Alert and Attentive}, 1 = \text{Scored 4 out of 5. Mildly distractible}, 2 = \text{Scored 3 out of 5. Moderate inattention with difficulty focusing}, 3 = \text{Scored 0-2 out of 5. Severe difficulty focusing, inability to follow instructions}. )</td>
</tr>
<tr>
<td>Delusions</td>
<td>0 1 2 3</td>
<td>Delusions can be of any type, but are most often persecutory. Rate as delusional if ideas are unlikely to be true yet are believed by the patient who cannot be dissuaded by logic. Delusional ideas cannot be explained otherwise by the patient’s usual cultural or religious background.</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Ask family members, nursing and clinical staff:</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Has the patient been suspicious or paranoid?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>If not available, ask the patient:</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Has anything strange happened to you here? Describe it and when it</td>
</tr>
<tr>
<td>Perceptual Disturbances and Hallucinations</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td><strong>Ask family members, nursing and clinical staff:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Does the patient appear to be seeing or hearing things that are not really there?”</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>If not available, ask the patient:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Has your mind been playing tricks on you so that you are not sure if what you are seeing or hearing is real? Tell me about it”.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 = Not present, 1 = Mildly suspicious, hypervigilant, or preoccupied, 2 = Unusual ideation that does not reach delusional proportions or could be plausible, 3 = Delusional hallucinations present</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Language</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Refer to MMSE language items and overall interview</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rate abnormalities of spoken, written or sign language that cannot be otherwise attributed to dialect or stuttering.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 = Normal language, 1 = Mild impairment including word-finding difficulty or problems with naming or fluency, 2 = Moderate impairment including comprehension difficulties or deficits in meaningful communication (semantic content), 3 = Severe impairment including nonsensical semantic content, word salad, muteness, or severely reduced comprehension</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lability of Affect</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rate the patient’s affect as the outward presentation of emotions and not as a description of what the patient feels.</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ask family members, nursing and clinical staff:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Does the patient become easily angry or tearful for no apparent reason?”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>If not available, ask the patient:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>“Do you have trouble controlling your emotions?”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 = Not present, 1 = Affect somewhat altered or incongruent to situation; changes over the course of hours; emotions are mostly under self-control, 2 = Affect is often inappropriate to the situation and intermittently changes over the course of minutes; emotions are not consistently under self-control, though they respond to redirection by others, 3 = Severe and consistent disinhibition of emotions; affect changes rapidly, is inappropriate to context, and does not respond to redirection by others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Thought Process</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate abnormalities of thinking processes based on</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Abnormalities                      |   |   | 3 | verbal or written output. Refer to “Additional Assessment Questions used to assist in scoring”
|                                 |   |   |   | 0 = Normal thought processes, 1 = Tangential or circumstantial, 2 = Associations loosely connected occasionally, but largely comprehensible, 3 = Associations loosely connected most of the time |
| Visuospatial Ability             |   |   |   | Refer to MMSE Drawing
|                                 | 0 | 1 | 2 | 3 |
| Motor Agitation                  |   |   |   | Rate by observation, including from other sources of observation such as by visitors, family and clinical staff. Do not include dyskinesia, tics, or chorea.
|                                 | 0 | 1 | 2 | 3 |
| Motor Retardation                |   |   |   | Rate movements by direct observation or from other sources of observation such as family, visitors, or clinical staff. Do not rate drowsiness or sleep.
|                                 | 0 | 1 | 2 | 3 |
| Sleep-Wake Cycle Disturbance     |   |   |   | Rate Sleep-Wake patterns using chart and observations
|                                 | 0 | 1 | 2 | 3 |

MODIFICATION REQUEST FORM

Form Instructions:

- To complete the form, press TAB or SHIFT TAB between boxes and enter an ‘X’ or text. For assistance, contact the Office for Research Protections.
- Since this form does not require signatures, the Modification Request Form and other revised documents may be submitted as separate email attachments.
- Submit any revised or new recruitment materials, informed consent forms, and all other materials as attachments to the application. Do NOT include within the application.
- Handwritten applications will NOT be accepted.

IRB Number: 31763

Project Title: Early Nurse Detection and Management of Acute Confusion: The END-DSD Project

Principal Investigator: Donna Fick
PSU User ID (e.g., abc123): dmf21

University Status (Faculty, Staff, Student, etc.): Faculty
Telephone Number: 865-9325

Email Address: dmf21@psu.edu
Dept: Nursing

College: School of Nursing
Campus: University Park

Mailing Address: 201 Health and Human Development East, University Park PA 16802

1. Is this study permanently closed to enrollment?

___x___ No → Skip to Question 3

_____ Yes → Answer Question 2

2. Is participant enrollment being re-opened via this modification request?

___x___ No

_____ Yes

3. Provide the following information:

- Total number of participants/samples currently approved for enrollment:
  - Patients = 80
  - Proxies = 80*
  - Nurses = 170*
- Number of participants/samples enrolled/entered: 330*
- Approved age range of participants:
  - Patients=65 and older
  - Proxies and Nurses = No age range

* The Proxy and Nurse participants were inadvertently not included on previous modifications.
4. Choose all of the changes that will be made. **Describe the requested changes in #2 below.**

- Location changes
- Conflict of interest changes
- Inclusion criteria changes
- Exclusion criteria changes
- Recruitment – Advertisement
- Compensation
- Adding a funding source
- Removing a funding source
- Adding personnel

If making changes to the informed consent form(s), recruitment materials and/or instruments, submit the revised forms for review.

5. Briefly describe the anticipated modifications.

There is a modification of the informal caregiver post-hospitalization interview guide. The modifications include a more formalized scripting of the interview guide, asking questions regarding symptoms recognized within the acute care setting to better match to the symptoms asked in the initial caregiver interview, and asking questions to more appropriately reflect their experience, and the experience of the patient, while in the acute care setting.

6. Describe the reason(s) for the anticipated modifications.

The informal caregiver post-hospitalization interview guide was modified based on pilot testing of the instrument. This tool was modified based on pilot testing and the changes were made in order to best capture the appropriate data from the informal caregivers related to their experience. Pilot testing found that the questions being asked on the previous version of the instrument did not best capture the desired data. The modifications did not alter the type information gathered from the informal caregivers from the previous version, but the goal is to improve the quality of the information gathered from informal caregivers during the telephone interview.

Please see the Informal Caregiver Post-Hospitalization Follow-Up Interview Guide.

None of the suggested modifications impact the risk of the study.

7. Does this modification affect the risk(s) to participants?

   \( X \) No
8. Does this modification affect the benefits to participants?
   __X_ No
   ____ Yes → Explain how the modification affects the benefits to participants:

9. Will this modification affect currently enrolled participants’ willingness to continue in the study (i.e., revised study procedures, changes in compensation, etc.)?
   ____ No currently enrolled participants → Skip to Question 11
   __X__ No → Skip to Question 11
   ____ Yes → Answer Question 10

10. How will currently enrolled participants be informed about the changes requested in this modification?
    ____ Participants will complete a new informed consent form. → Submit the new informed consent form for review.
    __X__ Participants will complete an addendum informed consent form. → Submit the addendum informed consent form for review.

11. Is an informed consent form being submitted with this modification?
    __X__ No → Finished with the “Modification Request Form”
    ____ Yes → Answer Questions 12 and 13

12. Is an existing and previously approved informed consent(s) form being revised and/or replaced?
    ____ No
    ____ Yes → Which consent form(s) are being revised and/or replaced? If possible, identify by Document Number.
    #1003

13. Is a new informed consent form(s) being added to the existing, previously approved consent form(s)?
    __X__ No
    ____ Yes
CRITERIA FOR APPROVAL CHECKLIST FOR AMENDMENTS

RESEARCH STUDY TITLE: Early Nurse Detection of Delirium Superimposed on Dementia

PRINCIPAL INVESTIGATOR: Donna Fick, PhD, RN  Date Completed: February 26, 2012

Study will be conducted on:  _X_ Altoona Hospital Campus  _X_ 7th Avenue Campus  _X_ Surgery Center

INSTRUCTIONS: Please review the attached amendment(s) submitted for the above-named study by the PI for this study. A copy of the Informed Consent Form is also provided for your review for appropriateness in view of the proposed amendments.

<table>
<thead>
<tr>
<th>Section A</th>
<th>Section B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investigators please complete Section A and attach a copy of your current consent form; verification will be conducted by members of the IRC in Section B. Thank you.</td>
<td>Investigator Use</td>
</tr>
<tr>
<td>QUESTION</td>
<td>YES</td>
</tr>
<tr>
<td>1. Has the protocol changed? If yes, please explain.</td>
<td></td>
</tr>
<tr>
<td>There is a modification of the informal caregiver post-hospitalization interview guide. The modifications include a more formalized scripting the of the interview guide, asking questions regarding symptoms recognized within the acute care setting to better match to the symptoms asked in the initial caregiver interview, and asking questions to more appropriately reflect their experience, and the experience of the patient, while in the acute care setting. There are no procedural changes in terms of consent or recruitment.</td>
<td></td>
</tr>
<tr>
<td>2. Have the risks to the study subjects changed? If yes, please explain.</td>
<td></td>
</tr>
<tr>
<td>3. Has the consent form changed? If yes, please explain. (Attach copy of current consent in use now.)</td>
<td></td>
</tr>
<tr>
<td>4. Will you be informing the study subjects about the amendments? Please explain. There are no procedural changes.</td>
<td></td>
</tr>
<tr>
<td>5. Does the amendment necessitate a change in the frequency of protocol review? If yes, please explain.</td>
<td>N/A</td>
</tr>
<tr>
<td>6. Final approval by IRC member</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Reviewed by: _______________________________  Date: _______________________________

(IRC Member Name)

IRC: Amendments (BLUE) 8/31/05; Revised 10/11/05; Revised 6/8/11
Andrea M. Yevchak, PhD(c), GCNS-BC, RN

EDUCATION

<table>
<thead>
<tr>
<th>Institution and Location</th>
<th>Field of Study</th>
<th>Degree, Year</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Pennsylvania State University</td>
<td>Nursing</td>
<td>Doctor of Philosophy</td>
</tr>
<tr>
<td>University Park, PA</td>
<td></td>
<td>Projected Graduation August, 2013</td>
</tr>
<tr>
<td>The Pennsylvania State University</td>
<td>Nursing</td>
<td>Master of Science</td>
</tr>
<tr>
<td>University Park, PA</td>
<td>Minor in Gerontology</td>
<td>May, 2007</td>
</tr>
<tr>
<td>The Pennsylvania State University</td>
<td>Nursing</td>
<td>Bachelor of Science</td>
</tr>
<tr>
<td>University Park, PA</td>
<td></td>
<td>May, 2005</td>
</tr>
</tbody>
</table>

Professional Licensure:
Pennsylvania Professional Nursing License RN 562995: Active
Gerontological Clinical Nurse Specialist certified by the American Nurses Credentialing Center: Active

PROFESSIONAL EXPERIENCE

Clinical Experience:
Registered Nurse; Mount Nittany Medical Center- Medical/Surgical/Orthopedic Unit (per diem status); State College, PA; June 2005- present
Wellness Nurse; The Village at Penn State; State College, PA; July 2007- August 2008

Research Experience:
Research Assistant; National Institutes of Health R01 (5 R01 NR012242 03): Reserve for Delirium Superimposed on Dementia (Reserve-DSD); PI Dr. Ann Kolanowski and Dr. Donna Fick; Fall 2011 – present; Role: Screening and Enrollment, Trainer for New Research Assistants for Screening and Enrollment/Daily Assessors, Daily Assessor, Interventionist, Data Review/Management/Entry, and General Office Tasks for Project Management; The Pennsylvania State University School of Nursing; University Park, PA

Research Assistant; National Institutes of Health R01 (5 R01 NR01104203): Early Nurse Detection of Delirium Superimposed on Dementia (END-DSD); PI Dr. Donna Fick; Summer 2010- present; Role: Screening and Enrollment at Two Sites, Trainer for New Research Assistants for Screening and Enrollment, Nurse Interventionist for Weekly Nurse Rounds at Two Sites, and Data Entry for Nursing Rounds; The Pennsylvania State University School of Nursing; University Park, PA

Awards and Scholarships:
2012-2013 Janet A. Williamson Graduate Award in Nursing from the Penn State School of Nursing
2009-2011 John A. Hartford Foundation and American Academy of Nursing Building Academic Geriatric Nursing Capacity (BAGNC) Scholar