Delirium and the Family Caregiver: The Need for Evidence-based Education Interventions

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Delirium, an acute confusional state, is experienced by many older adults. Although there is substantial research on risk factors and etiology, we hypothesized that there is a dearth of information on educating the family caregivers of delirious older patients. A date-specific (2000–2013) literature review of articles, written in English, was conducted in several major databases using keyword searches. This systematic review focused on 2 objectives: (1) investigate published studies on the impact of delirium on the family regarding caring for a loved one; and (2) determine if there are interventions that have provided family caregivers with education and/or coping skills to recognize and/or manage delirium. A systematic elimination provided outcomes that met both objectives. Thirty articles addressed impact on family caregivers (objective 1); only 7 addressed caregiver education regarding the delirious state of a loved one (objective 2). Few studies consider the impact of delirium on family caregivers and even fewer studies focus on how to manage delirium in loved ones. With increased risks to older adult patients, high cost of care, and the preventable nature of delirium, family caregiver education may be an important tactic to improve outcomes for both patient and caregiver.

Key words: Delirium and family caregivers, Caregiver education interventions, Delirium and caregiver support

Delirium is known as an acute confusional state that is experienced by many hospitalized patients especially in older adults. Delirium presents as disturbances of cognitive function that can affect orientation, attention, memory, and planning (Meagher, 2001). Currently, there is substantial research on the risk factors, causes, and treatment of delirium (Conn & Lieff, 2001; Gleason, 2003; Pae, Marks, Han, Patkar, & Masand, 2008; Rabinowitz, Murphy, Nagle, Bodor, Kennedy, & Hirdes, 2003). However, there is a dearth of information educating the delirious patient’s family members and informal caregivers of this medical condition. Although there is recognition that delirium impacts family caregivers, there is little documentation on how they can recognize delirium or help care for a loved one experiencing delirium, both of which may help family members to cope with an often frightening situation. (Bruera et al., 2009; Morita, Hirai, Sakaguchi, Tsuneto, & Shima, 2004).

Delirium

Delirious episodes are characterized by an abrupt onset of disturbances of consciousness, attention, cognition, and
perception that tend to fluctuate over the course of the day and are associated with a high level of morbidity and mortality (Breitbart, Gibson, & Tremblay, 2002).

The *Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition* (DSM-IV, 1994) defines delirium by the following four criteria:

1. Disturbance of consciousness with reduced ability to focus, shift, or sustain attention;
2. A change in cognition or development of a perceptual disturbance that is not better accounted for by a pre-existing, established, or evolving dementia;
3. Develops over a short period of time, usually hours to days, and tends to fluctuate over the course of a day; and
4. Tends to be caused by the direct physiological consequences of a general medical condition (p. 142).

Delirium is rarely caused by a single factor; it is often a multifactorial syndrome, the most common causes being drugs and toxins, infections, metabolic disturbances, brain disorders, systemic organ failure, and physical disorders (Francis & Young, 2013). According to the Werner, US Census Bureau (2010), older adults aged 65 and older comprise 13% of the US population. Although older adults represent the smallest percentage of population by age, they account for 43% of hospital inpatient care days (Hall, DeFrances, Williams, Golosinskiy, & Schwartzman, 2010). Thirty percent (30%) of older adults, 65 years of age or older, who are hospitalized present with delirium at some point during their stay. If the older adult is a surgical patient they are 10%–50% more likely to experience delirium (US Census Bureau, 2010). This percentage is even higher if the patient is frail or has cardiac surgery. Additionally, 70% of intensive care unit (ICU) patients, 10% of emergency department patients, 42% of patients on hospice units, and 16% of patients in post acute care settings are also at risk of presenting with delirium (US Census Bureau, 2010). Although delirium can occur from a variety of causes, it is noted to occur in 68%–90% of terminally ill cancer patients’ right before death (Morita, Akechi, & Ikenaga, 2007). It should be noted that delirium does not have to be superimposed on cancer to exhibit the typical delirious signs or for it to be considered a medical emergency.

Leslie and Inouye (2011) found that patients with delirium have a 62% greater risk of mortality than those who do not experience delirium. This contributes to total health costs attributable to delirium as ranging from $16,303 to $64,421 (in 2005 dollars) per patient, with national health care costs of $143 billion to $152 billion each year (Leslie & Inouye, 2011). There are two disturbing facts about delirium: (a) it is considered to be a preventable condition (Inouye, 2006) and (b) when people present with delirium it is often misdiagnosed and therefore mistreated (Pae et al., 2008; Rabinowitz et al., 2003). Inouye (2006) has determined that 40% of delirium cases within the hospital setting could be prevented if doctors, nurses, and patients’ families were aware of its causes and made small but meaningful changes in how patients are treated. Prompt recognition of the symptoms and proper management can shorten the duration of the episode, alleviate suffering, and reduce costs.

The Family Caregiver

The family caregiver is most commonly defined as a spouse, family member, partner, or friend who is the primary person assisting with care (Naylor, Hirschman, Bowles, Bixby, Konick-McMahan, & Stephens, 2007). For this article, the term family caregiver will be used to cover the broad spectrum of informal caregivers. These caregivers are distinguished from formal caregivers in that they are not connected to a social service or health care system. Informal caregivers also tend not to have formal education or training as a health or social service provider. An estimated 21% of households in the United States are impacted by caregiving responsibilities (National Alliance for Caregiving/AARP, 2004). Informal caregivers provide an estimated 90% of the long-term care (Institute on Medicine, 2008) that is needed by an immediate family member, with 83% of family caregivers providing care for a relative (Family Caregiver Alliance, 2005).

Methods

A systematic literature review focused on two objectives relative to medical and gerontological literature on delirium for older adults: (1) to investigate published studies that address the impact on the family regarding caring for a loved one with delirium; and (2) to determine if there are interventions that have provided family caregivers with education and/or coping skills to recognize and/or manage delirium. A thorough, multistep date-specific (2000–2013) literature search was conducted exploring peer-reviewed articles written in English on delirium in relation to family caregivers.

Phase 1

The following search engines were utilized: MEDLINE-PubMed, MEDLINE EBSCO, MEDLINE Proquest, CINAHL, and Cochrane Collection Plus. Four search terms were used to search for the most relevant articles. These terms included: (a) Delirium AND Family Caregiver, (b) Delirium AND Family AND Intervention, (c) Impact AND Delirium AND Family, and (d) Family Caregiver Assessment Method AND Delirium.
Once searches were conducted, all citation abstracts (N = 333) were reviewed and duplicates were deleted (N = 221), with 112 citations remaining. As none of the remaining citations were from Cochrane Collection Plus, this search engine was eliminated. See Table 1 for number of citations that coincided with each of the remaining four search engines.

The following inclusion and exclusion criteria were applied when reading the remaining 112 abstracts to determine which articles would be accessed. Inclusion criteria included: (a) delirium was main clinical focus (required), and at least one of the following (b–d): (b) recognized that delirium is a source of stress for the family caregiver, (c) discussed an intervention for the family caregiver or intervention for the patient that involved the family caregiver, and (d) provided education about delirium to family caregivers. Exclusion criteria included: (a) clinical focus was dementia or another comorbidity of delirium, (b) object of article was solely on diagnosis/treatment/recognition of delirium, (c) delirium was only discussed as a symptom of another medical condition, and (d) focus was on nursing care of patients with delirium. It was determined that 30 citations met some or all of the above criteria.

Phase 2
In order to further investigate impact on the family (objective 1) and to determine if there are interventions that have provided family caregivers with education, training, and/or coping skills to recognize and/or manage delirium (objective 2), the process of elimination continued. The 30 articles that met Phase 1 criteria were accessed and read to ascertain the following: (a) setting and population, (b) goal of study/article, and (c) if the authors addressed the impact of the patient’s delirium on the family caregiver. As all 30 articles addressed impact on the family caregivers, they were then read a second time to evaluate (a) whether an education or training intervention was provided and (b) what outcomes (if any) resulted from the caregiver intervention. This reading resulted in eight articles being discarded, as they didn’t address education interventions. Of the remaining 22 articles, 15 articles stated that education is important for family caregivers, but there were no interventions actually provided or endorsed by the authors; these too were discarded and 7 articles remained. The abstract/article citation elimination numbers are presented in Figure 1.

The remaining articles addressed both objectives and specifically offered education/training interventions to family caregivers. These articles were read once more focusing on four categories of importance to caregiver education/training: (1) Delirium Etiology and Symptoms, (2) Delirium Recognition and Prevention, (3) Impact of Delirium on Family, and (4) Educating Family about Delirium. We then assessed to what degree the authors addressed these categories within each article and whether the authors (a) mentioned the topic, (b) provided some information on the topic and/or (c) provided detailed information on the topic. See Table 2.

Results
Objective 1: Impact on the Family Caregiver
The findings revealed that caregiving is often a full time responsibility; resulting in fear, fatigue, frustration, depression, illness, financial burden, and overall stress for the family caregivers (Breitbart et al., 2002; Morita et al., 2004). The delirious loved one is extensively dependent on this caregiver for care; with activities of daily living at the top of the list (Lawlor, & Bruera, 2002; Miller, Campbell, Moore, & Schofield, 2004). The family caregiver must play the role of decision maker, ensure that the patient’s needs are met, and remain protective of the patient (Goy & Ganzani, 2003). Providing this level of care can negatively impact the psychological well-being of the caregiver (Bruera et al., 2009). The amount of time spent managing their loved one can isolate the caregiver from society and much needed positive support from family and friends (Steis et al., 2012). Naylor and colleagues (2007) stated that family members expressed that they felt they were missing

| Table 1. Search results (duplicate citations deleted) |
|---------------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
|                                 | MEDLINE-Pubmed | MEDLINE-EBSCO   | MEDLINE-Proquest | CINAHL          | Total           |
| 1. Delirium AND Family Caregiver| 4               | 1               | 14              | 1               | 20              |
| 2. Delirium AND Family AND Intervention| 22 | 1               | 35              | 2               | 60              |
| 2. Impact AND Delirium AND Family | 15 | 0               | 4               | 2               | 21*             |
| 3. Family Caregiver Assessment Method AND Delirium| 0 | 1               | 9               | 1               | 11              |
| Total                          | 41             | 3               | 62              | 6               | 112             |

Note: “Impact of Delirium on Family” was found in four additional articles that were not revealed under this search heading.
out on life, wished they could escape from the situation, and felt emotionally drained.

When delirium presents in older adult patients, it can be a very distressing event for the caregiver for many reasons. Family members are often unsure of how to approach agitated behaviors that are common during delirious episodes (Cobb, Glantz, Nicholas, Martin, Paul-Simon, Cole, & Corless, 2000). When patients and their family caregivers were interviewed to recall their level of distress during an illness that included delirious episodes, two studies found that spouses and caregivers were significantly more distressed by the patient’s delirium than were the actual patients or their nurses (Bruera et al., 2009; Breitbart et al., 2009). The caregiver frequently misinterprets the etiology of delirium (i.e., believing the patient is in excruciating pain or near death) and leads him or her to question their ability to continue to care for the patient (Lawlor & Bruera, 2002). When delirium occurs in the setting of terminal illness, it creates a barrier to meaningful communication and family members are deeply concerned about their ability to convey their final goodbyes (Cohen et al., 2009; Goy & Ganzani, 2003; Lawlor & Bruera, 2002; Milisen, Steeman, & Foreman, 2004). Despite their level of distress, Cohen and colleagues (2009) found that family caregivers expressed an interest to learn more about how to better help their loved ones and how to maintain their own well-being. Providing family caregivers with tools to recognize delirium or assist with care for their loved one with delirium was cited as being of importance in reducing the impact on family caregivers (Black, Boore, & Parahoo, 2011; Gagnon, Allard, Gagnon, Mérette, & Tardif, 2012; Rosenbloom-Brunton, Henneman, & Inouye, 2010; Steis et al., 2012).

**Objective 2: Education/Training for Family Caregivers**

Fifteen studies called attention to the fact that educating family members of patients at high risk of developing delirium or with delirium can be beneficial both to the patient and to the caregiver. Education about delirium may help family members to recognize the symptoms of delirium so that they are less uncertain and fearful when episodes occur. Providing information to the family may help to explain that agitation from delirium can often be palliated and would help them to understand the rationale behind medical interventions (Cobb et al., 2000). Education would also help caregivers to adopt appropriate attitudes regarding delirium and proper ways to deal with symptoms (Cohen et al., 2009; Gagnon et al., 2012). Several studies point to an important realization that the family caregiver observes the patient’s behaviors most frequently and is the ideal figure to recognize subtle changes in cognition (Bruera et al., 2009; Leonard, Agar, Mason, & Lawlor, 2008; Miller et al., 2004; Rosenbloom-Brunton et al., 2010; Steis et al., 2012). As a major source of knowledge regarding the patient’s needs, routines, and manifestations of discomfort, an educated caregiver may be the best resource in recognizing symptoms of delirium and aiding in a loved one’s care (Gagnon et al., 2002; Leonard et al., 2008; Miller et al., 2004; Steis et al., 2012). Therefore, providing evidenced-based education to the family caregiver will not only lessen their anxiety and distress but also employ their knowledge to provide earlier detection and treatment of delirium. Seven articles were cited as providing education to family caregivers. See Table 3.

The first two articles presented in Table 3 (Black et al., 2011; Gagnon et al., 2012) were inconclusive. Each offered verbal education about delirium plus some written information in the form of a pamphlet or written recommendations on delirium for family caregivers. In each case the intervention failed to reduce delirium incidence, severity, or duration. There was no mention if impact on family caregivers was reduced or exacerbated by the failed outcomes. The next five articles offered more promising family education interventions with the hope that their involvement would reduce the incidence of delirium in their loved ones and therefore reduce the stress and fear that comes with supporting a delirious family member (Martinez, Tobar, Beddings, Vallejo, & Fuentes, 2012; Otani et al., 2013; Rosenbloom-Brunton et al., 2010; Steis et al., 2012). Martinez and colleagues (2012) found that nonpharmacological intervention carried out by family members reduced the risk of developing delirium. There were six elements included in the intervention: (a) A brief family education session (approximately 10 min) was required that included...
a specifically designed pamphlet; (b) provision of a clock and calendar in the room; (c) sensory stimulation such as glasses, dentures, and hearing aids; (d) objects in the room that were familiar to the patients; (e) family members reorienting the patient (current date and time, recent events); and (f) extended visitation times (5 h daily). Steis and colleagues (2012) conducted research with community dwelling older adults. The researchers provided verbal education along with an educational handout, and also taught caregivers to use the Family-Confusional Assessment Method, referred to as FAM-CAM ©2000 Hospital Elder Life Program; to report symptoms of delirium electronically. Family caregivers reported being comfortable using FAM-CAM and stated that it helped them to feel more confident in caring for a family member with delirium. The study conducted by Otani and colleagues (2013) educated family caregivers with literature specifically developed to help family members understand the nature, causes, and implications of delirium. The leaflet was evaluated as useful for family caregivers and found to help family members cope. Gagnon and colleagues (2002) and Rosenbloom-Brunton and colleagues (2010) both utilized nursing staff to assist with educating/training family caregivers and focused on early detection of delirium. Family Caregivers in the Gagnon and colleagues’ (2002) study reported that their confidence improved in reacting to delirium

<table>
<thead>
<tr>
<th>Article title</th>
<th>Informational categories</th>
<th>Delirium etiology and symptoms</th>
<th>Delirium recognition and prevention</th>
<th>Impact of delirium on family</th>
<th>Educating family about delirium</th>
</tr>
</thead>
<tbody>
<tr>
<td>The effect of nurse-facilitated family participation in the psychological care of the critically ill patient Black, Boore, and Parahoo (2011)</td>
<td>+</td>
<td>++</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Preventing delirium in an acute hospital using a nonpharmacological intervention Martinez, Tobar, Reddings, Vallejo, and Fuentes (2012)</td>
<td>+</td>
<td>+++</td>
<td>+</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Detection of delirium in community-dwelling persons with dementia Steis et al. (2012)</td>
<td>++</td>
<td>+</td>
<td>++</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Usefulness of the leaflet-based intervention for family members of terminally ill cancer patients with delirium Otani et al. (2013)</td>
<td>+</td>
<td>+</td>
<td>++</td>
<td>+++</td>
<td>+++</td>
</tr>
<tr>
<td>Feasibility of family participation in a delirium prevention program for hospitalized older adults Rosenbloom-Brunton, Henneman, and Inouye (2010)</td>
<td>+</td>
<td>++</td>
<td>++</td>
<td>+++</td>
<td>+++</td>
</tr>
</tbody>
</table>

Notes: + = Authors mention the topic; ++ = Authors mention and provide some information on the topic; +++ = Authors mention and provide detailed information on the topic.
### Table 3. Education/training intervention results

<table>
<thead>
<tr>
<th>Article</th>
<th>Setting/population</th>
<th>Type of education provided</th>
<th>Purpose of educating family</th>
<th>Outcome of the education intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gagnon, Allard, Gagnon, Merète, and Tardif (2012)</td>
<td>Canada. Terminal cancer patients in palliative care centers</td>
<td>Verbal education about delirium and symptoms, plus American College of Physicians’ recommendation for avoiding symptoms of confusion in advanced cancer</td>
<td>To determine if family participation in multicomponent intervention would prevent delirium</td>
<td>Multicomponent intervention did not reduce delirium incidence, severity, or duration</td>
</tr>
<tr>
<td>Black, Boore, and Parahoo (2011)</td>
<td>Ireland. Critical illness patients in the intensive care unit</td>
<td>Verbal introduction to delirium and booklet that contained practical guidelines for understanding delirium, providing psychological care, and how to communicate with delirious patients</td>
<td>To determine if family participation in psychological care would decrease the extent of delirium or improve psychological recovery following illness</td>
<td>Family participation did not reduce incidence of delirium but patients did demonstrate better psychological recovery after admission to critical care</td>
</tr>
<tr>
<td>Martinez, Tobar, Beddings, Vallejo, and Fuentes (2012)</td>
<td>Chile. Hospitalized internal medicine patients.</td>
<td>Verbal explanation of delirium accompanied by specially designed pamphlet. Plus five other patient orientation elements carried out by the family members</td>
<td>To determine if nonpharmacological intervention delivered by family members would reduce incidence of delirium</td>
<td>Nonpharmacological intervention carried out by family members reduced risk of developing delirium</td>
</tr>
<tr>
<td>Steis, et al. (2012)</td>
<td>United States. Community dwelling adults with delirium superimposed on dementia</td>
<td>Verbal education from a research assistant along with an educational handout. Taught to use the FAM-CAM to report symptoms of delirium electronically</td>
<td>To explore feasibility of engaging family caregivers to electronically report observations of delirium symptoms in community dwelling older adults with dementia</td>
<td>Caregivers felt comfortable using the FAM-CAM, some said they would continue to use the questions, and most said FAM-CAM helped them feel more confident in caring for family member</td>
</tr>
<tr>
<td>Gagnon, Charbonneau, Allard, and Soulard (2002)</td>
<td>Canada. Patients with advanced cancer.</td>
<td>Informational brochure designed to educate family caregiver on delirium was presented verbally by nurse then offered to the caregiver to read and keep.</td>
<td>To help family caregivers cope with delirium and eventually to contribute to early detection.</td>
<td>Improved confidence in reacting to delirium symptoms, reassuring, provided a message of hope, and felt ready to confront delirium symptoms.</td>
</tr>
<tr>
<td>Otani et al. (2013)</td>
<td>Japan. Patients with terminal cancer in palliative care centers</td>
<td>Leaflet about the nature, causes, and implications of delirium in terminal cancer</td>
<td>To determine level of family-perceived usefulness of leaflet about delirium</td>
<td>Leaflet was evaluated as useful for family members. Could help family members cope</td>
</tr>
<tr>
<td>Rosenbloom-Brunton, Henneman, &amp; Inouye (2010)</td>
<td>United States. Older adults in acute care hospital setting</td>
<td>Family caregivers were given detailed instruction in five intervention protocols of Family-HELP by a member of the research team.</td>
<td>To determine Family success when participating in Family-HELP, the multi-component intervention for delirium prevention.</td>
<td>Study results support the feasibility of family participation in delirium prevention. Family-HELP demonstrates that active engagement of family caregivers in preventive interventions for delirium is feasible</td>
</tr>
</tbody>
</table>

Notes: FAM-CAM = Family-Confusional Assessment Method; HELP = Hospital Elder Life Program.
symptoms, reassuring their loved one and providing a message of hope. Rosenbloom-Brunton and colleagues (2010) designed the Family-HELP, where hospital nurses working with the staff focused Hospital Elder Life Program (©1999, Sharon K. Inouye, MD, MPH) trained family caregivers on four intervention protocols adapted to be amenable to family implementation. Although this family intervention is limited to hospitals that employ the HELP model and study results indicate that the effect of Family-HELP on delirium prevention remains unclear; family caregivers with successful experiences reported that they and their loved one felt empowered, supported, respected, and enjoyed the process of developing relationships with the staff (Rosenbloom-Brunton et al., 2010).

Discussion

With the increased risk to older adult patients, the high cost of care, and the preventable nature of delirium, there must be additional care models that can be instituted to decrease the prevalence of delirium or at least provide additional supportive care. Although there is a clear need for improvement in the care of the delirious person, this study hopes to call attention to the fact that the family caregiver is a critical element in this care. Acting as a primary caregiver for an older adult is stressful in itself. Being caught off guard by a delirious episode or living in fear that delirium may occur at any moment and what it implies about the person’s condition creates an additional burden. Although limited, these studies support that providing family caregivers with an effective means of education provides an opportunity to enhance their caregiving. Because delirium may commonly extend past a hospital stay, or may occur in the home at the onset of an illness or infection, we cannot stress enough the importance for caregivers to have an understanding of delirium and to know what approaches they can take when caring for a loved one with this life threatening acute insult. Although these caregivers aren’t medically trained and cannot provide additional medical care, they are in the optimum position to: (a) recognize delirium symptom onset and contact health care providers sooner and/or (b) provide an intervention for a loved one experiencing delirium to assist health care providers that may result in reducing the duration of a delirious episode.

This review has identified the means of family caregiver education that have been implemented and tested to date, but further research is needed to determine which method(s) is/are most effective. Having trained health care professionals provide education to family members exhibits a promising approach as indicated in the studies presented. However, additional options exist, such as engaging public health departments, state offices on aging, and community service organizations, such as Area Agencies on Aging, to create more societal awareness of the deleterious effects associated with delirium and ways of caring for a loved one. Although to date there is no proven education or training intervention for family caregivers in managing the delirium of a loved one, the most promising research appears to be those that include multicomponent interventions for delirium recognition and treatment; benefiting the patient as well as the family caregiver. Martinez and colleagues (2012) provided a nonpharmacologic six element intervention specifically designed for family caregivers. Possibly, this may be a good place to begin; further investigating the efficacy of this six element intervention model and how to effectively teach it to family caregivers.

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