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# Educating Family Caregivers for Older Adults About Delirium: A Systematic Review

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## **ABSTRACT**

**Background:** Delirium in older adults is considered a medical emergency; it contributes to a cascade of functional decline and to increased mortality. Early recognition of delirium symptoms is critical to prevent these negative consequences. Family caregivers who are educated about delirium could partner with nurses and other healthcare professionals in early recognition of delirium symptoms. Before implementing such partnership models, it is important to examine the effectiveness of educating family caregivers about delirium.

**Aims:** To examine whether providing education on delirium to family caregivers improved their knowledge, emotional state, or response in reducing the incidence of delirium in older adults.

**Methods:** For this systematic review, we conducted literature searches in CINAHL, Cochrane Library, Medline, PsycINFO, Web of Science, Social Sciences in ProQuest, Dissertations and Theses, and the Virginia Henderson Global Nursing eRepository for studies published in the English language between January 2000 and June 2015. Criteria for inclusion were: (a) primary focus on educating family caregivers for older adults about delirium; (b) use of experimental, quasi-experimental, or comparative design; (c) measured family caregiver outcomes of delirium knowledge, emotional state, or response in reducing delirium incidence in older adults; and (d) published in the English language. Articles were appraised using Melnyk's rapid critical appraisal guides.

**Results:** Seven studies met the review criteria. Four studies found that family caregivers' delirium knowledge increased; two noted that delirium incidence in older adults declined; and one study reported less distress following receipt of education.

**Linking Evidence to Action:** Providing family caregivers with information about delirium can be beneficial for both family caregivers and older adults. However, rigorous evaluation of education programs for family caregivers about delirium is needed.

**Keywords:** family caregivers; delirium; educational intervention; older adults

## Introduction

Delirium is a common, serious problem in older adults. It occurs in up to 64% of hospitalized older adults and also has been observed in as many as 85% of those receiving palliative care (Greaves, Vojkovic, Nikoletti, White, & Yuen, 2008; Inouye, Westendorp, & Saczynski, 2014). In addition, delirium rates as high as 39% have been reported in community-dwelling older adults (Mathillas, Olofsson, Lovheim, & Gustafson, 2013).

Delirium is characterized by sudden onset of confusion, inattention, perceptual disturbance, and illogical or incoherent speech. Older adults who have delirium may fluctuate between hyperactive states with symptoms of agitation or hallucinations and hypoactive states with symptoms of excessive drowsiness or lethargy (Leslie & Inouye, 2011; Sykes, 2012). Delirium places older adults at an increased risk for falls, prolonged hospital stays, nursing home placement, and a cascade of functional decline. The duration of delirium is associated with these negative outcomes and with

increased mortality (Dasgupta & Brymer, [2014](#); Rudolph & Marcantonio, [2011](#); Saczynski et al., [2012](#)).

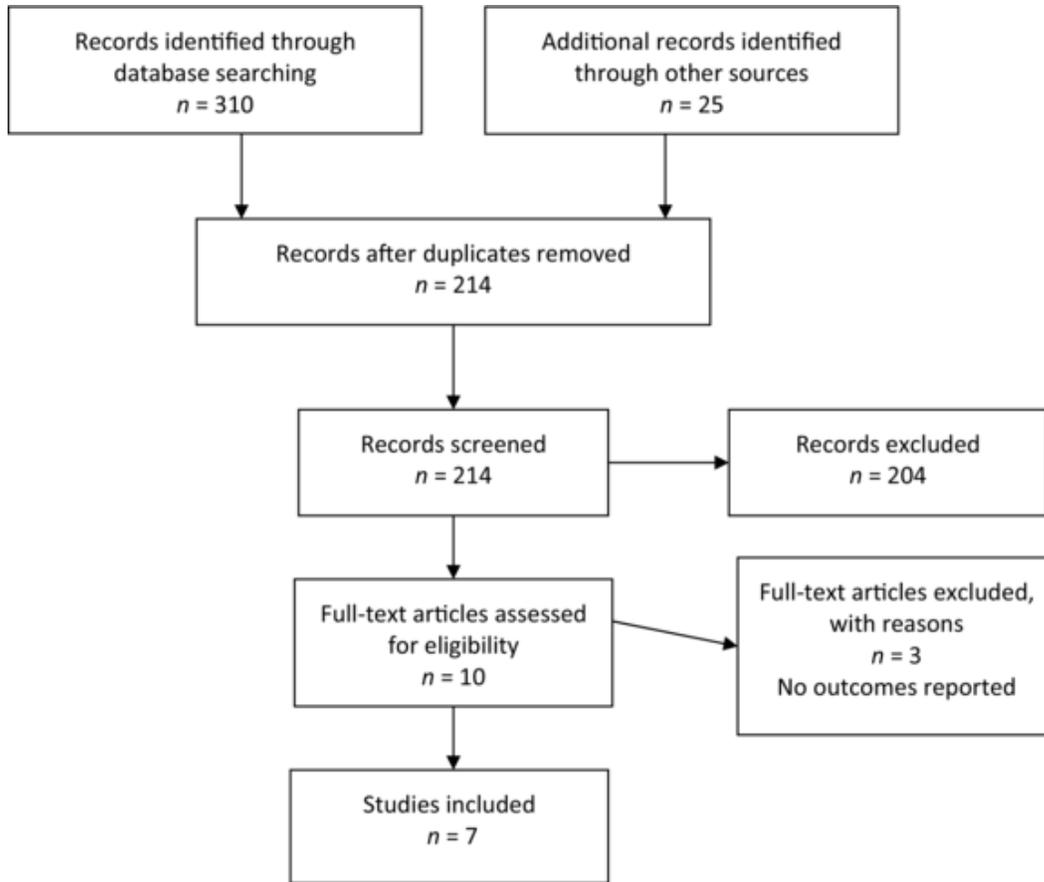
Multiple factors cause or contribute to delirium. Some of these factors include infection, adverse reaction to medications, hypoxia, uncontrolled pain, dehydration, hypoglycemia, electrolyte imbalance, and environmental factors such as use of physical restraints, poor vision, or hearing (American Geriatrics Society Expert Panel on Postoperative Delirium in Older Adults, [2015](#); Meier, [2012](#)). Unlike dementia, delirium is often reversible when recognized early and the underlying cause is treated. However, healthcare providers who are unfamiliar with the older adult's cognitive baseline often fail to recognize delirium symptoms (Boustani et al., [2010](#); Greer et al., [2011](#)). Family caregivers, who are familiar with the older adult's usual behaviors, are likely partners in early recognition of delirium. However, family caregivers might attribute delirium symptoms to normal aging or dementia (Bull, [2011](#); Bull, Boaz, & Sjostedt, [2014](#); Toye, Matthews, Hill, & Maher, [2014](#)).

The findings of descriptive studies indicate that family caregivers experience anxiety, fear, and distress when faced with older adults who have delirium symptoms (Bruera et al., [2009](#); Toye et al., [2014](#)). Previous reviews support these statements and suggest that family caregivers might benefit from education about delirium (Carbone & Gugliucci, [2015](#); Halloway, [2014](#)). However, literature reviews did not specifically address the effectiveness of educating family caregivers about delirium symptoms on outcomes for either family caregivers or older adults. This prompted us to examine whether providing education on delirium to family caregivers improved their knowledge, emotional state, or response in reducing the incidence of delirium in older adults. Specific emotional states of interest included distress and anxiety levels because these were noted in findings of qualitative studies. One might assume that an education intervention that provided information about what to expect might improve family caregivers' emotional state and when information about strategies to prevent delirium are included it might lead to application of knowledge and thereby reduce delirium incidence in older adults (Otani et al. [2014](#)). Examining the evidence for improving outcomes following the receipt of education about delirium is an

essential antecedent to implementing partnership models in nursing practice.

## Methods

For this systematic review, we conducted literature searches in CINAHL, Cochrane Library, Medline, PsycINFO, Web of Science, and Social Sciences in ProQuest for studies published in the English language between January 2000 and June 2015. We searched for gray literature in Dissertations and Theses and the Virginia Henderson Global Nursing eRepository. Search strategies included a combination of subject headings and keywords for each concept—delirium, family caregivers, and educational interventions. We reviewed reference lists and articles citing relevant papers and performed similar article searches to identify additional studies not retrieved through initial database searching. A total of 335 records were retrieved, including 121 duplicates. When duplicates were eliminated, the result was 214 unique records. See flow chart in Figure 1. Thirteen non-English language articles were identified in the search prior to application of the English language limit; however, none of these articles met the inclusion criteria. The abstracts of the unique records were reviewed by the authors to ascertain whether they met the following inclusion criteria: (a) primary focus on educating family caregivers for older adults about delirium; (b) use of experimental, quasi-experimental, or comparative design; (c) measured family caregivers outcomes of delirium knowledge, emotional states, or response in reducing delirium incidence for older adults; and (d) published in the English language. Studies that did not report on these outcomes were excluded. The articles were independently reviewed by two of the authors using Melnyk's rapid critical appraisal guides (Melnyk & Fine-Overholt, 2015). The criteria on the appraisal guides included key elements such as methodological quality, level of evidence, outcomes measured, sampling approach, findings, statistical and clinical significance, and usefulness of the findings for practice and further research. In synthesizing the findings, articles were grouped by level of evidence and outcomes measured.



**Figure 1.** Flow diagram of articles records retrieved.

## Findings

Seven articles met the inclusion criteria and are summarized in Table 1. None of the articles were systematic reviews of randomized controlled trials, Level I, which are considered the highest level of evidence (Melnik & Fine-Overholt, 2015). One study (Martinez, Tobar, Beddings, Vallejo, & Fuentes, 2012) used a randomized design (Level II). The focus of the intervention in this study was on providing family caregivers with information about activities to perform while visiting the hospitalized older adult to prevent delirium. Nurses performed daily assessments for delirium using the Confusion Assessment Method (CAM). The results indicated that older adults with family caregivers in the intervention group had significantly fewer cases of delirium than the control group (5.6% vs. 13.3%,  $p = .027$ ). As noted in Table 1, two studies were categorized as level III (Gagnon, Allard, Gagnon,

Merette, & Tardif, [2012](#); Rosenbloom & Fick, [2014](#)). In both studies, family caregivers received information about delirium and its symptoms. Gagnon and colleagues ([2012](#)) found no significant differences in delirium incidence for the older adults with cancer in the intervention and control groups.

Citation	Country	Purpose and framework	Design method	Sample setting	Measurement tools	Data analysis	Level of evidence and addresses PICO question
Black et al. (2011)	Ireland	Framework: Neuman Systems Model Purpose: Examine effects of nurse-facilitated family participation in psychological care on psychologic recovery and delirium extent	Comparative time series Intervention and control groups	Setting: Inner city public hospital Sample: Convenience sample N = 69 in intervention and N = 69 in control Group Power analysis (.80) and effect size (.50) indicated N = 63 needed per group	Seventy of illness was measured with the TISS-28, which has been cross-validated with the TISS-76 (r = .93) Intensive Care Delirium Screening Checklist (Cronbach's alpha .71-.79) Sickness Impact Profile – no validity reported but has been used in studies on critical care	Mean delirium scores between groups was not statistically significant Older adults with family caregivers in the intervention group had fewer positive delirium scores (29% vs. 77%) than comparison group	Level IV Addresses PICO question partially – in older adults fewer cases of delirium were reported though the results were not statistically significant. Family caregiver knowledge and/or outcomes was not addressed
Gagnon et al. (2002)	Canada	Framework: None Purpose: Develop a psychoeducational intervention framework, a brochure to be used for the intervention, assess the intervention's effects on family and professional caregivers	Three-phase study-phase 3 was nonrandomized comparative groups Phases I and 2 descriptive to provide information for developing intervention	Setting: Terminal cancer care center Sample: Phase I – 21 FC interviewed over 2 months for psychoeducational intervention development Phase II – 20 FC interview for brochure development Phase III – Consecutive sampling of FC. Intervention group = 58, comparison group = 66 FC	Measurement outcome: Family caregiver knowledge of delirium Confusion Rating Scale (Maison Michel Sarrazin in house instrument) No validity and reliability of tools reported	Phase III - Statistically significant differences were reported for Knowledge of Delirium: frequency of delirium (p = .038); causes of delirium (p = .032); Perceived competence: Adequate knowledge for decisions (p = .006); Attitudes: Information should be given to all FC (p = .009)	Level III Partially addressed PICO question – family caregiver education had no effect on the delirium incidence rate or severity of cases of delirium
Gagnon, Allard, Gagnon, Merette, & Tardif (2012)	Canada	Framework: None Purpose: Tested the effectiveness of a multicomponent intervention to reduce the incidence and severity of delirium	Nonrandomized design Measured delirium incidence in the older adults with cancer Family members were educated about delirium and symptoms using a developed procedure not described	Setting: Hospice and palliative care facilities Sample: Intervention group (N = 674), comparison group (N = 842)	Confusion Rating Scale – validity and reliability not reported	No statistically significant differences between the intervention and control groups	Level III Partially addressed PICO question – family caregiver education had no effect on the delirium incidence rate or severity of cases of delirium

(Continued)

Citation	Country	Purpose and framework	Design method	Sample setting	Measurement tools	Data analysis	Level of evidence and addresses PICO question
Keyser et al. (2012)	Canada	Framework: Knowledge to Action process (clarifies language translation) Purpose: Examine if knowledge translation product for families of community-dwelling older adults would increase knowledge related to prevention and identification of delirium	Design: Pre-post (no control group) Four phases – I. Focus groups II. Education sessions with families of community-dwelling older adults III. Semistructured telephone or e-mail interview IV. Intervention - seven group educational sessions held with 16 participants	Setting: Community sample: N = 11 completed; 25 consented family caregivers for community-dwelling older adults	Phase II Education Session Package – consent forms, pre- and post test, questionnaire, reference card, two pamphlets on presented material Vancouver Island Health Authority resources. Validity and reliability of tools not reported	Statistically significant increase in median knowledge of delirium score ( $W = 0, p = .05$ )	Level IV Partially addresses PICO – improved outcomes for family caregiver knowledge of delirium. Effects on delirium in older adults not addressed
Martinez et al. (2012)	Chile	Framework: None Purpose: Determine if a nonpharmacological intervention about delirium given to FC could reduce the incidence of delirium during hospitalization	Design: Randomized Methods: Nonpharmacological intervention included six elements: (a) Education about acute confusion syndromes, (b) provision of a clock/calendar, (c) avoiding sensory deprivation, (d) presence of familiar objects, (e) reorientation, and (f) extended visitation	Setting: Internal medicine ward of a naval hospital Sample: Enrolled intervention group N = 144, control group N = 143. 13 were lost to follow-up (4 in treatment group, 9 in control group)	CAM – patients were assessed daily for delirium symptoms	Statistically significant differences in the frequency of delirium cases between groups (5.6% vs. 13.3%; $CI .19-.92, p = .027$ )	Level II Partially addresses PICO – outcomes were improved for older adults with family caregivers in intervention group

(Continued)

Citation	Country	Purpose and framework	Design method	Sample setting	Measurement tools	Data analysis	Level of evidence and addresses PICO question
Rosenbloom and Fick (2014)	United States	Framework: None Purpose: Feasibility study to pilot intervention	Quasi-experimental pretest-posttest Intervention: NFCPM Intervention, a three-component intervention consisting of delirium education, a nurse/FC partnership module, and Unit Nurse Champion	Setting: 2 acute care academic medical centers in Boston, MA, USA. Sample: Triad groups of an older adult, FC & staff nurse. Intervention group - N = 14 triads Control group - N = 14 triads	Delirium knowledge was measured using 3 instruments: Knowledge of Delirium Questionnaire, case vignettes, Expectations Regarding Aging Scale. Attitudes toward partnership was measured with an adapted version of the Family-Centered Care Survey Satisfaction with the NFCPM was examined using four open-ended questions in in-person interviews of staff nurses and by phone calls to FC	Statistically significant improvement in knowledge of delirium ( $p = .02$ ) Family caregivers reported satisfaction with the intervention	Level III Partially addresses PICO – Improved family caregiver knowledge results in improved family caregiver outcomes
Otani et al. (2014)	Japan	Framework: None Purpose: Assess the effects of a leaflet based intervention on family perceived distress, the need for improvements in professional care for delirium, and family knowledge about the causes of delirium	Quasi-Experimental, with a historical control with family caregiver for EOL patients with cancer. Method: Clinicians used leaflets about delirium to teach family caregivers about causes and implications of delirium in cancer patients at EOL. Healthcare professionals viewed education video on delirium in half-day workshop and received instructions on use of leaflet	N = 113 intervention N = 242 historical control 77% response rate	No formal validation of delirium knowledge assessment instrument No validity and reliability of tools reported	Median interval from patient death to completing survey significantly shorter in intervention group (9 vs. 11 months) No group differences reported in perceived distress (M3.6 and 3.5, respectively) or in need for improvements in professional care Statistically significantly higher scores for intervention group on delirium knowledge for two causes of delirium ( $p < .001$ )	Level IV Partially addresses PICO – family caregiver knowledge improved No difference in distress scores

CAM = Confusion Assessment Method; EOL = end of life; FC = family caregiver.

In contrast, Rosenbloom and Fick (2014) focused on delirium knowledge rather than delirium incidence. They reported that family caregivers' knowledge of delirium improved significantly following the intervention ( $p = .02$ ). As noted in Table 1, the remaining four studies were all level IV, case-control, and cohort studies. Three of the studies (Gagnon et al., 2002; Keyser, Buchanan, & Edge, 2012; and Otani et al., 2014) measured the outcome, family caregiver delirium knowledge. All of these studies reported that family caregiver knowledge of delirium increased postintervention; Keyser and colleagues reported a statistically significant increase in the median knowledge score ( $p = .05$ ). Only the study by Otani and colleagues (2014) measured family caregiver distress in addition to delirium knowledge. Family caregivers in the intervention group reported less distress than those in the control group. The fourth level IV study (Black, Boore, & Parahoo, 2011) focused on decreased delirium incidence and found that the older adults who had family caregivers in the intervention group had fewer positive delirium scores than the comparison group (29% vs. 77%). However, there was no statistically significant difference in the mean delirium scores of the intervention and control groups.

These studies were conducted in a variety of settings. Three of the studies were conducted in Canada (Gagnon et al., 2002, 2012; Keyser et al., 2012), one in Chile (Martinez et al., 2012), one in the United States (Rosenbloom & Fick, 2014), one in Ireland (Black, Boore, & Parahoo, 2011), and one in Japan (Otani et al., 2014). Three of the samples comprised family caregivers for terminally ill patients with cancer receiving end-of-life care. Three studies obtained samples from hospitalized older adults; one of these was from an intensive care unit. Only one Canadian study obtained a sample of family caregivers for community-dwelling older adults (Keyser et al., 2012). All of the studies used nonprobability samples. Sample sizes ranged from 11 (Keyser et al., 2012) to 1,516 (Gagnon et al., 2012). One study reported sample power to detect difference as .80 with an effect size of .50 (Black et al., 2011). Only the study by Martinez and colleagues (2012) employed random assignment to the intervention and control groups.

Only two studies utilized a conceptual framework. Keyser and colleagues (2012) used the Knowledge to Action framework to develop

the education sessions for family caregivers of community-dwelling older adults. Using this framework, the researchers initially conducted focus groups with family caregivers to identify their need for information about delirium. Black and colleagues (2010) used the Neuman Systems Model to guide the study and the nurse-facilitated family participation in psychological care intervention. Use of a conceptual framework to guide the intervention in these studies strengthened the evidence for practice and also enhanced the reproducibility with other samples and across other settings (Fawcett & Garity, 2009).

In summary, the key outcomes measured in these studies of family caregiver education included delirium knowledge, improved emotional state (specifically, less distress), and reduced delirium incidence in the older adult. Four studies reported family caregiver knowledge of delirium increased; two found the delirium incidence in older adults decreased; and one reported less distress in the family caregivers in the intervention group. Although none of the studies measured all three outcomes, each of the studies was well designed for the respective level of evidence. Random assignment to control groups might not have been feasible in settings that used one clinical site because of potential for contamination of data if family caregivers interacted with each other. All of the studies that measured delirium incidence used valid, reliable instruments. Reports of increased delirium knowledge following receipt of education were consistent across studies and levels of evidence. However, the investigators did not provide information on the psychometric properties of the delirium knowledge and distress instruments. This might reflect the state of the science regarding these instruments at the time the studies were conducted. These studies provide a solid foundation for future studies that evaluate effectiveness of educating family caregivers about delirium. As noted previously, the studies were well designed and used valid, reliable instruments to measure delirium incidence. However, future studies using designs that include control groups are needed.

## **Discussion**

Providing education to family caregivers about delirium has potential benefits for both the older adult and the family caregiver.

Alleviating family caregiver distress would be an important outcome in end of life care as it might enable family members to be present with the older adult and provide care. Of the three studies conducted with family caregivers of terminally ill patients, only Otani and colleagues (2014) measured family caregiver distress. It is also important to consider timing for obtaining these data. In the study conducted by Otani and colleagues (2014), the data on distress were obtained several weeks to months after the patient's death. It is possible that grief and the passage of time might attenuate the family caregiver's recall of any distress related to delirium. Timing is often a delicate balance between obtaining data proximate to the event and being sensitive to anticipatory grief that family caregivers might experience.

Other studies focused on family caregiver response in reducing delirium incidence, clearly a benefit for the older adult. Two studies with family caregivers of hospitalized older adults (Black et al., 2011; Martinez et al., 2012) found fewer cases of delirium in older adults whose family caregivers received education. Although the study by Black and colleagues (2011) did not find statistically significant differences between delirium incidences in older adults whose family members received the education versus those who did not receive education about delirium, it appeared there might be practical significance (Polit & Beck, 2012, p. 478). The finding of a 29% occurrence of delirium in the intervention group was considerably lower than the 77% in the control group. Considering the cascade of functional decline in older adults that often results from delirium, having fewer occurrences of delirium might result in better long-term outcomes for the older adult. It is also important to note that Black and colleagues used a theoretical framework to guide their study. Theory provides evidence for nursing practice, thereby giving additional credence to the study findings and its potential relevance for practice and future research (Fawcett & Garity, 2009).

In contrast, two other studies that focused on the outcome of delirium incidence with terminally ill cancer patients did not find a reduction in delirium incidence (Gagnon et al., 2002, 2012). Given the physiologic changes that occur at the end of life that can contribute to delirium, one might not expect that providing education would decrease the incidence of delirium. The clinical situation, the nature of the educational intervention, and whether the education could alter the

outcome are important factors to consider in the study design and in evaluating the evidence for practice. Unfortunately, the lack of detail describing the intervention in these studies makes it difficult to evaluate whether the education provided to the family caregiver might have an effect on delirium incidence.

It is important to note that though there were few intervention studies, the perspectives were from five different countries and included acute care, palliative care, and community settings. This suggests that developing best practices in educating family caregivers is of global interest.

Most of the studies that met the criteria for inclusion in this review had methodological flaws; their findings should be viewed with caution. Only the study by Martinez and colleagues (2012) used a randomized design. The lack of randomized designs in other studies makes it difficult to ascertain whether the results could be attributed to the intervention or to a confounding variable.

On the positive side, the studies that measured delirium incidence in the older adult reported using standardized, valid, reliable tools in assessing for delirium. Despite the methodological flaws in these studies, it is important to note that none of the studies reported any adverse effects of the delirium education on either the family caregiver or the older adult. In fact, Rosenbloom and Fick (2014) found family caregivers reported satisfaction with the intervention. This finding is encouraging given that patient and family teaching is a key nursing role. Although none of the studies measured all three outcomes, the findings highlight the gap in knowledge and the need for further research examining the effectiveness of providing education about delirium to family caregivers.

## **Limitations**

It is important to note that the articles, theses, and dissertations included in the literature search for this evidence review were limited to those in the English language. Also, the search did not include conference proceedings. Nonetheless, our findings support the need for further research given the limited number of studies in the 15-year period from 2000 to 2015.

## Conclusions And Recommendations

The state of the science on the outcomes of educating family caregivers about delirium in older adults is limited. Evaluating the effectiveness of providing family caregivers with education about delirium is a critical and relatively untapped area for research. Previous studies clearly indicate family members were distressed by observing delirium symptoms in their older adult (Bruera et al., [2009](#); Toye et al., [2014](#)); education could alleviate that distress. Furthermore, with the duration of delirium recognized as a factor contributing to the cascade of functional decline in older adults (Dasgupta & Brymer, [2014](#); Rudolph & Marcantonio, [2011](#); Saczynski et al., [2012](#)), family caregivers are potential partners in early recognition of delirium symptoms. Educating family caregivers about delirium, its symptoms and the importance of contacting the older adult's healthcare provider when symptoms are noted has the potential to result in early interventions to ameliorate the delirium. Also, the findings of the study by Martinez and colleagues ([2012](#)) indicate that family caregivers have a critical role in preventing delirium in hospitalized older adults. Rosenbloom and Fick ([2014](#)) were innovative in their approach to educating both family caregivers and nurses about delirium. This two-pronged approach might be essential in creating effective patient-family-provider partnership models that aim to decrease delirium incidence and duration. From the studies reviewed, one can also conclude that providing education about delirium was not viewed as harmful to either the family caregiver or the older adult.

However, there are several recommendations for future research. First, in building the evidence for best practice in educating family caregivers about delirium, it is essential to provide a sufficiently detailed description of the intervention so that readers can evaluate whether the intervention might logically impact the outcomes measured in the study or be feasible in their setting. The lack of a detailed description of the intervention also makes replication difficult. Describing the conceptual framework used in developing the intervention could facilitate clinicians in reproducing the desired outcomes in their setting. Second, the use of valid, reliable measures of outcomes is essential. Valid, reliable measures currently exist for

assessing presence or absence of delirium. However, there are fewer, valid, reliable measures of family caregiver delirium knowledge. This suggests the need to examine psychometric properties of these measures and include information on validity and reliability of the measures in publications. Third, it is important to know whether the family caregiver's increased knowledge results in actions that lead to either prevention of delirium or early interventions for its treatment. Fourth, longitudinal studies might provide evidence to support the effects of family caregiver education on the older adult's functional outcomes following hospitalization. Much work remains to build the evidence on outcomes of providing family caregivers with education about delirium. Future work might also examine best practices in providing family caregivers with education about delirium.

## **Linking Evidence To Action**

- Providing family caregivers with information about delirium can be beneficial for both family caregiver and older adult.
- Conducting rigorous evaluation of education programs for family caregivers about delirium is needed.
- Preparing nurses and other healthcare professionals to partner with family caregivers in early recognition of delirium symptoms might be necessary step in implementing partnership models.

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