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A Family-Focused Delirium Educational Initiative With Practice and Research Implications

Christina May Paulson,

Vanderbilt University Medical Center, Nashville, Tennessee, USA

Todd Monroe,

Schools of Nursing and Medicine, Vanderbilt University, Nashville, Tennessee, USA

Graham J. Mcdougall Jr, and

School of Nursing, The University of Alabama, Tuscaloosa, Alabama, USA

Donna M. Fick

School of Nursing, The Pennsylvania State University, University Park, Pennsylvania, USA

Abstract

Delirium is burdensome and psychologically distressing for formal and informal caregivers, yet family caregivers often have very little understanding or knowledge about delirium. As part of a large multisite intervention study, the Early Nurse Detection of Delirium Superimposed on Dementia (END-DSD), the authors identified a need for family educational materials. This educational initiative's purpose was to develop a delirium admission brochure for family members to aid in the prevention and earlier identification of delirium during hospitalization. A brochure was developed using an iterative approach with an expert panel. Following three iterations, a final brochure was approved. The authors found that an iterative expert consensus approach can be used to develop a brochure for families. Major content areas were helping families understand the difference between delirium and dementia, signs and symptoms of delirium, causes of delirium, and strategies family members can use to prevent delirium. A caregiver-focused educational brochure is one intervention to use in targeting older adults hospitalized with delirium.

Keywords

delirium; dementia; education; family members; family practice education; geriatric; geriatric education; older adults

INTRODUCTION

Delirium is a challenging and costly public health problem. *Delirium* is defined as an acute decline in cognition and a disturbance in awareness and attention (American Psychiatric Association, 2013). Delirium commonly occurs in older adults who are hospitalized with

Address correspondence to Christina May Paulson, Vanderbilt University Medical Center, 1211 Medical Center Drive, Nashville, TN 37232, USA. christina.m.paulson@vanderbilt.edu.

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prevalence at admission ranging from 10% to 31% and an occurrence rate per admission varying between 11% and 42% (Siddiqi, House, & Holmes, 2006). Delirium can lead to serious negative consequences in older adults who are hospitalized and is frequently associated with increased mortality, increased length of stay, and possible institutionalization (Siddiqi, House, & Holmes, 2006). Delirium associated costs exceed \$160 billion per year in the United States alone (Leslie, Marcantonio, Zhang, Leo-Summers, & Inouye, 2008). Delirium can occur in people with dementia further complicating its diagnosis. The prevalence of delirium in older adults with dementia is estimated between 13% and 19% in the community to more than 40% in the hospital (Fick, Steis, Waller, & Inouye, 2013). It is difficult for health care professionals to recognize delirium in patients with dementia because of overlapping symptoms and limited knowledge about baseline mental status (Fick & Mion, 2008). Failure to recognize delirium in people with dementia may result in unnecessary physical, emotional, and mental distress leading to increased suffering and pain (Paulson, Monroe, & Mion, 2014). Given the difficulty in recognizing delirium in people with dementia, we posited that family members and informal caregivers could serve an important role in helping hospital staff recognize delirium.

Caregivers are commonly defined as “formal” caregivers such as licensed nurses and physicians but can also include “informal” caregivers such as families and significant others. Not surprisingly, most intervention studies aimed at recognizing delirium usually focus on formal caregivers; however, a paucity of studies exist examining the use of informal caregivers in the management of delirium. Using a standard literature search in PUBMED with the terms *delirium education* and *family education for delirium* two studies were located describing interventions focused on family education for hospitalized older adults with delirium (Gagnon et al., 2002; Rosenbloom-Burnton, Henneman, & Inouye, 2010). Rosenbloom-Burnton, Henneman, & Inouye (2010) examined a preventive focused intervention aimed at training family members to complete five protocols targeting four risk factors for delirium including impairment in cognition, activities of daily living, vision, and hearing. The five protocols involved providing orientation focused memory cues (e.g., clock, family photos), providing cognitive stimulating activities (e.g., discussing the news, reminiscing), ensuring the older adults have access to and wears their glasses and hearing aids, and encouraging daily ambulation and assistance (Rosenbloom-Burton, Henneman, & Inouye, 2010). Findings showed that each of the five protocols was completed by the family caregivers at least 75% of the time (Rosenbloom-Burton, Henneman, & Inouye, 2010). With the primary aim to assess baseline knowledge about delirium in family members, the second study was constructed of three phases (Gagnon et al., 2002). During Phase 1, health care professionals and family caregivers were selected into focus groups and provided interview questions in relation to their role and knowledge about delirium including content, knowledge of delirium, past experience with delirium, and distribution of brochure. During Phase 2, a separate set of family caregivers reviewed the brochure and was interviewed about their impression and distribution of brochure. Phase 3 involved a control group and an intervention group where family caregivers reviewed the brochure with the bedside nurse dictating what material within the brochure they would receive. As a result, the bedside nurse would perform an intervention from within the brochure to assist in managing the delirium. The family caregivers were reevaluated with a questionnaire about the overall

attitude of the brochure, dissemination, and content in regards to understanding delirium compared to a control group that did not receive interventions (Gagnon et al., 2002). The authors found that family members are rarely aware of delirium and that family members do not know how to identify delirium; yet by providing an educational brochure to family members their knowledge increased aiding in appropriate reactions to delirium (Gagnon et al., 2002). Together, these studies demonstrate that participation in the care of hospitalized older adults by informal caregivers is feasible, and there is a need for education of these caregivers.

Helping families understand the risk factors and causes of delirium can assist the entire health care team in managing delirium. Many factors may influence the development of delirium such as dementia, medications, anesthetics, dehydration, alcohol misuse, pain, sensory impairment, chemical imbalances, vitamin deficiencies, and infections (Inouye, 1999). Managing the complex causes of delirium in the hospitalized older adults is critical to resolving delirium and treatment with nonpharmacological multicomponent approaches is an effective strategy (Inouye, 2006; Inouye, Bogardus, Baker, Leo-Summers, & Cooney, 2000; O'Mahony, Murthy, Akunne, Young, & Guideline Development Group, 2011). Findings from one study found that nonpharmacological interventions may help lead to a lower rate of incidence of delirium, decreased number of days of delirium, and fewer numbers of episodes of delirium (Inouye, 1999). Primary prevention with significant emphasis on providing nonpharmacological interventions plays a strong role in delirium prevention and dissemination of education to family members.

Thus, informal caregivers, such as family members, are an important and underused resource in the management of delirium. The purpose of this educational initiative was to develop an evidence-based educational brochure that frontline nurses can use to provide information about delirium to families and to initiate family-driven interventions in the management of delirium.

METHOD

Setting

The current educational initiative study setting was a 24-bed inpatient medicine and acute care of the elderly unit (ACE) at a large academic medical center in metropolitan Nashville, TN.

Process

The delirium brochure educational project fits directly into a large multisite intervention study, the Early Nurse Detection of Delirium Superimposed on Dementia (END-DSD) being researched at the setting. The parent study is a cluster randomized clinical trial and has four components, education (initial and ongoing education), computerized decision support, unit champions and a feedback loop. The parent study is guided by Rogers' (2003) diffusion of innovation framework for adoption of the intervention and for the unit champion and the education dimension of the study. Thus, the sites are facilitated to be adaptive and flexible and to fit the education into their local needs and context. The research staff that round with

the nurses are from the parent study and assist the direct care staff in developing delirium educational content and delivery modes that meets their needs first and then is shared with the other sites to adapt if needed. As the parent study was being conducted, a unit champion identified the need for family educational materials. A group of experts from the parent study used an iterative approach to achieve the final version of the educational material for the brochure. Three rounds of iterative communication were needed until a consensus was reached.

Expert Panel

The expert panel consisted of two medical doctors trained in geriatrics, four doctoral nursing students in clinical geriatrics, and four advanced practice nurses with geriatric expertise. Based on the expert panel's feedback, a staff nurse performed the revisions and resubmitted the brochure for review. Patient and caregivers feedback was not assessed during the iterative process. The process began as a bullet point text, black-and-white handout. During the first iteration, feedback on content and presentation led to the development of a simple brochure. During the second iteration, the panel continued to clarify and develop content and a graphics department was consulted to improve the overall attractiveness of the brochure. A final iteration led to the brochure approved by the expert panel (see Figure 1).

Procedures

Vanderbilt University's Institutional Review Board approved the delirium educational brochure project. Following a standard literature search and a review of available materials located in the hospital, we located one paper form only discharge handout and an Intensive Care Unit Delirium Brochure that was available online (ICU Delirium & Cognitive Group, 2010). Several criteria were considered during review of the brochure's content such as reading level, evidence-based content, person-centered content, and graphics with consideration from the National Institute of Aging recommendations on *Making Your Printed Health Materials Senior Friendly* (National Institute on Aging, 2008). The brochure provides direct and specific lists with three to five key points in separate sections focusing on action steps while avoiding long descriptive sentences to ensure clarity. The brochure's layout is simple, with breaks for the eyes to relax and allow readers to focus. The brochure is ranked as a 4.9 on the Flesch-Kincaid Grade level test, indicating a fourth grader should be able to read based on U.S. standards. The expert consensus group identified several key topics relevant to the main goal of helping caregivers identify and manage delirium including: a description of delirium, differences between delirium and dementia, signs and symptoms of delirium, causes of delirium, and strategies the caregivers could use to help prevent and manage delirium in their family member based on multicomponent intervention studies (Gagnon et al., 2002; Inouye, 1999; Rapp, 2001; Rosenbloom-Burton, Henneman, & Inouye, 2010).

Implementation

The brochure was shared with a total of 32 nurses and 14 ancillary staff members on the ACE unit both shifts. The charge nurse, nurse educator, and the Early Nurse Detection of Delirium Superimposed on Dementia study staff provided the frontline nurses information

about the brochure and how to access the brochure. We planned that the brochure would be disseminated to family caregivers on admission; however, the brochure was available anytime during hospital stay. The color version was available for the first 4 months in paper form. Due to the concern of continued availability and financial expenses of the color version, the Patient Education Department of the academic medical center approved access to the black-and-white version of the brochure through the electronic documentation system available to all faculty and staff 4 months after release of the brochure on the unit. Over the initial 16 months that the document was made internally available via the electronic documentation system, it has been viewed 56 times. Twenty months after completion of the brochure, it is available for medical professionals, patients, and family members on Vanderbilt University Medical Center for Health Services Research website: www.icudelirium.org by the Intensive Care Unit Delirium and Cognitive Study Group.

A quantitative survey with a section for one question requesting narrative responses was completed by seven out of 19 ACE unit nurses and included ACE unit staff members who have been on the unit since release of the brochure. The survey consisted of six out of seven closed-ended questions, including *yes* or *no* and answers ranging from *strongly disagree* to *strongly agree*. The last questions allowed for narrative data to be extracted determining any barriers or positives of the initiative. Forty-three percent of the staff reported that they had used either the color version or the black-and-white version on at least one occasion. All staff either *strongly agreed* or *agreed* with the statement, “The brochure is easy to read and provides appropriate delirium education to family caregivers”. There was concern about the accessibility of the brochure and continued education to the nursing staff about the brochure and its use based on responses from the narrative section of the survey. Nearly 86% stated they would continue to recommend the brochure to other nurses, and 100% of the respondents stated they plan to recommend the use the delirium brochure to patients and families.

DISCUSSION

The goal of the delirium brochure was to provide delirium education to family caregivers and empower them to be an integral part of the health care team. The brochure was driven by experts and nurses to develop an easy-to-read educational brochure targeted for family caregivers using an iterative process. This initiative provided an easy-to-read educational brochure for family caregivers with the recommendation of continued use by the nursing staff on the targeted setting. The analysis of the survey showed a drive to use the brochure in the future but lacked a current dissemination of the brochure by the nursing staff. This warrants a closer evaluation of the current dissemination of the brochure to improve the number of patients and families who receive the brochure. Despite the small sample size of surveyed nursing staff, lack of evaluation of family caregivers, and use in only one unit within a hospital setting, there is a need for further research in regards to family-driven educational initiative with the basis of family-driven interventions to preventing and managing delirium. Further research is warranted to develop more education to patients and caregivers regarding delirium and techniques to prevent and manage the symptoms of delirium, especially in regards to the use of nonpharmacological interventions. As the world’s population increases in the number of older adults, a family caregiver driven

educational initiative and interventions to assist in preventing and managing delirium, a prevalent diagnosis among older adults, is supported.

We believe family members can learn to use nonpharmacological interventions to improve delirium symptoms in hospitalized older adults. Nonpharmacological interventions described in the brochure provide a way for family members to assist in delirium care without direct nursing supervision. The evidence-based brochure developed from this educational initiative is being used hospital wide and is freely available for others to use.

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FIGURE 1.
Final iteration of approved educational brochure.