The death of a family member is a moment that matters. Family members of nursing home residents have reported difficulty recognizing the dying trajectory and being unprepared when death occurred (Forbes, Bern-Klug, & Gessert, 2000). Length of time as a family caregiver did not predict preparedness for the death. Research now indicates that family members who are prepared for the death of a loved one through clear communication with health professionals are less likely to experience complicated grief responses (Hebert, Dang, & Schulz, 2006).

A paradigm shift has occurred: Routine after-death bereavement support is no longer supported by empirical evidence (Neimeyer, 2004). Therefore, nursing homes, stretched for professional staff, should not allocate professional resources to after-death grief support programs but rather should educate and encourage RNs to prepare family members in advance of the death of a nursing home resident. In particular, RNs need to put greater emphasis on helping families “see what we see” and making the sometimes subtle, often-unrecognized, dying trajectory of a nursing home resident transparent.

**PURPOSE**

The purpose of the evidence-based practice guideline, *Family Preparedness and End of Life Support Before the Death of a Nursing Home Resident* (Davidson, 2009), is to provide information for end-of-life (EOL) support of family members before the death of a nursing home resident. This guideline is intended for frontline staff (e.g., RNs, licensed practical nurses [LPNs], care attendants, physicians, social workers, chaplains) who care for elderly residents and provide support to the older adults’ families in nursing homes. The guideline helps frontline staff in developing, implementing, and evaluating their own knowledge, skills, and abilities related to preparing family caregivers for the death of a loved one and implementing EOL support interventions. It is also intended for managers and administrators who develop policy and procedures and allocate resources in nursing home settings. The full text of this evidence-based practice guideline is available from The University of Iowa Hartford Center of Geriatric Nursing Excellence.

**OVERVIEW**

The death of a nursing home resident is a frequent event, perhaps even part of the subculture and “reason for being” of nursing homes. Although approximately 20% of all deaths in the United States occur in nursing homes (Bercovitz, Decker, Jones, & Remsburg, 2008), the nursing home industry and regulatory bodies do not acknowledge palliative care as a primary function of nursing homes (Philips et al., 2006). The current prevailing mandate and
message—that nursing homes are for the rehabilitation and functional maintenance of all residents—is not achievable nor desirable for residents at EOL. However, an equally pervasive belief, held by regulatory bodies and the general public, is that nursing home residents die as a result of poor care and not because of advanced age and end-stage chronic illnesses (Oliver, Porock, & Oliver, 2006). Until the nursing home industry, regulators, and the general public can acknowledge that nursing homes are “de facto hospices” (Philips et al., 2006, p. 422), nursing home residents approaching EOL will not receive appropriate palliative care. Additionally, most nursing homes are hampered in their efforts to establish and maintain expertise in EOL care due to high staff turnover and staff shortages. Furthermore, the low ratios of professionals, with 70% to 90% of care being provided by minimally trained nursing assistants, makes the translation of evidence into practice very challenging (Ersek & Wilson, 2003; Forbes et al., 2000).

Because nursing homes are not viewed as caring for dying individuals, less than half of nursing homes surveyed reported holding memorial services for residents or providing any other EOL support (Ersek & Wilson, 2003; Moss, Braunwolff, & Rubenstein, 2002; Oliver, Porock, Zweig, Rantz, & Petroski, 2003). Few articles in the scholarly literature specifically address EOL care in nursing homes, and only one journal article reviewed EOL programs in nursing home settings (Murphy, Hanrahan, & Luchins, 1997). Although Neimeyer (2004) reported that “research on bereavement and grief has burgeoned in the past 20 years” (p. 495), Oliver, Porock, and Zweig (2004), in their meta-analysis of the 1995 to 2002 literature, reported that not one clinical trial on EOL care in nursing homes was discovered. Unfortunately, this trend is unchanged, and no clinical trials pertaining to EOL care in nursing homes were found for this literature review encompassing 2000 to 2008.

Another reason for the paucity of research and clinical practice literature relating to EOL support surrounding the death of a nursing home resident may be that such deaths are seen as “on time” and in keeping with societal expectations (Sheehan & Schirm, 2003). The death of an elderly nursing home resident has been described by bereaved family members as both a blessing and a tragedy. Although family members grieve for the loss of a loved one, death is frequently characterized as releasing the older adult from an unwanted, diminished existence (Forbes et al., 2000). EOL, in some circumstances, may lead to a lessening of distress for family members of nursing home residents. For example, family caregivers of residents with dementia showed declines in symptoms of depression within 3 months of the death (Burton, Haley, & Small, 2006; Neimeyer, 2004).

The previous version of this evidence-based practice guideline was published in 2002. In the intervening years, a paradigm shift occurred in the area of bereavement support. Although the population of family members grieving the death of a nursing home resident has not been studied specifically, recent evidence has demonstrated that most bereaved individuals cope effectively and their grief is self-limiting; thus, routine grief intervention is ineffective and unnecessary for the approximately 90% of bereaved people experiencing normal grief (Kissane et al., 2006; Neimeyer, 2004; Schut & Stroebe, 2005; Zhang, El-Jawahri, & Prigerson, 2006). Only approximately 10% of bereaved individuals experience complicated grief disorder (Barry, Kasl, & Prigerson, 2002; Neimeyer, 2004; Zhang et al., 2006). More important, complicated grief disorder can only be diagnosed when at least 6 months have passed following the death; therefore, screening recently bereaved individuals for risk of poor bereavement outcome is no longer supported by empirical evidence (Neimeyer, 2004; Zhang et al., 2006).

Because death is part of the nursing home experience, one might expect that family members are prepared for the death of their loved one. However, length of time caring for an older adult approaching EOL does not predict preparedness for death when it actually occurs (Barry et al., 2002; Forbes et al., 2000; Hebert, Dang, & Schulz, 2006). In addition, no relationship was found between length of stay in a nursing home, the resident’s age, or the resident’s ability to communicate or to participate in decision making and the obstacles to palliative care that older adults will experience (Travis et al., 2002). Many family caregivers do not recognize the progressive deterioration of their loved one in a nursing home as signaling EOL—what Forbes et al. (2000) appropriately labeled the “unrecognized trajectory of dying” (p. 251). This sense of being unprepared is a concern to nursing home staff because lack of preparedness is associated with complicated grief reaction (Barry et al., 2002).

Given this new evidence pertaining to the importance of death preparedness, the Family Preparedness evidence-based practice guideline describes 10 key elements to enhance family preparedness and EOL support in nursing home settings. These elements are summarized below.

**DESCRIPTION OF THE PRACTICE**

Providing clear interventions in the care plan gives frontline nursing home staff confidence and direction in assisting family members in EOL situations where staff often feel stressed and uncertain (Burack & Chichin, 2001). The RN, who is usually the team leader and most prevalent frontline professional, is ideally...
situated to take accountability for implementing and coordinating the following family preparedness and EOL support interventions.

**Staff Development**

Successful and consistent implementation of family preparedness and EOL support depends on the knowledge, skills, and abilities of frontline workers (e.g., RNs, LPNs, care attendants, physicians, social workers, chaplains, volunteers). The need for training of nursing home staff to improve the standard of EOL care for residents and their family members is widely acknowledged (Ersek & Wilson, 2003; Katz, Sidell, & Komaromy, 2001; Moss et al., 2002; Neimeyer, 2004; Oliver et al., 2004; Rice, Coleman, Fish, Levy, & Kutner, 2004). Staff education topics should include the dying process, with particular emphasis on recognition of the dying trajectory (Forbes et al., 2000; Kehl, 2006); communication skills specific to preparing family members for the dying trajectory, death, and bereavement (Forbes et al., 2000; Hebert, Dang, & Schulz, 2006; Herbert, Prigerson, Schulz, & Arnold, 2006); culturally sensitive EOL care (Hebert, Prigerson, et al., 2006); clinical indicators of dying; and the use of opioid and non-opioid medications for nursing home residents without a cancer diagnosis (Parker et al., 2005).

**Use of Clinical Indicators Of Mortality**

Because the current prevailing mandate and message is that nursing homes are for the rehabilitation and functional maintenance of all residents, identifying and communicating that a resident is approaching EOL is implicitly discouraged. However, failure to identify this phase of life is the most powerful obstacle to effective palliation and EOL plans of care in nursing home residents (Travis et al., 2002). Too often, the diagnosis of dying occurs only hours or days before death, when it is too late to achieve high quality EOL care (Porock et al., 2005).

Experienced RNs are rarely surprised by the death of a nursing home resident, but those same nurses often have difficulty pinpointing exactly how they knew that a resident was approaching death. Research has identified indicators of the trajectory of dying, which may assist RNs and others to identify and communicate approaching EOL. Some of these indicators include weight loss and low body mass index, increasing dependence with activities of daily living, and lower respiratory infection in the past 90 days (Flacker & Kiely, 2003; Forbes et al., 2000; Mehr et al., 2001; Porock et al., 2005). The full list of indicators of the dying trajectory is provided in the *Family Preparedness* guideline (Davidson, 2009). For nursing homes using the Minimum Data Set (MDS) tool, Porock et al. (2005) developed an “MDS Mortality Risk Index Point System” to help with identifying the EOL trajectory of nursing home residents.

**Labeling the Resident as “Terminal”**

Family members and nursing home residents expect physicians to label the resident as “terminal” when the time comes (Forbes et al., 2000). Although family members expect the physician to tell them that their family member is dying, many physicians also find it difficult to identify the dying trajectory of nursing home residents. Physicians have expressed difficulty in predicting mortality in the absence of a clear terminal diagnosis. The indicators of mortality as indicated above can be used by physicians to guide resident-specific mortality prediction (Flacker & Kiely, 2003). RNs can facilitate family preparedness by ensuring ongoing involvement of the nursing home resident’s physician in determining approaching EOL and communicating with residents and family members about dying and death (Hebert, Dang, & Schulz, 2006).

**Communication Among Decision Makers**

Lack of communication among decision makers and failure to agree on a course for EOL care are two common obstacles to implementing palliation for nursing home residents (Travis et al., 2002). Clear communication with health professionals is a major predictor of family preparedness for EOL (Hebert, Prigerson, et al., 2006). Leadership by RNs to facilitate open discussions about dying, death, and bereavement would likely improve caregiver well-being (Hebert, Dang, & Schulz, 2006). The RN should ensure a family conference is arranged with the physician, primary nurse, and other members of the health care team for open discussion of the resident’s approaching EOL (Hebert, Dang, & Schulz, 2006). Following the conference, the RN must ensure the dying resident’s care plan is updated to incorporate the personal, cultural, and spiritual EOL values, beliefs, and practices that are important to the resident and family caregivers (Kehl, 2006) and that advance care planning documents (e.g., living wills, personal directives) are incorporated into care plans (Hanson, Henderson, & Menon, 2002).

Family members and nursing home residents often adhere to the “myth of rehabilitation” because the formal message of nursing homes is one of rehabilitation and maintenance of function. False hope in rehabilitation can become a major barrier to advanced care planning (Hanson et al., 2002; Oliver et al., 2006). In addition, most people seek to avoid regret in decision making, and in particular, “worry about making decisions that in hindsight might prove to be incorrect and that they will regret” (Travis et al., 2002, p. 343). Such worries make a “do everything possible” response seem like the only safe decision for family members confronted with making decisions about the res-
ident’s approaching EOL. RNs and physicians must anticipate both the myth of rehabilitation and regret avoidance and be prepared to allay family caregiver uncertainty about their loved one nearing EOL and the low benefit/high burden of aggressive curative care (Travis et al., 2002).

Family Member Recognition of Disease Progression, Dying Trajectory, and the Dying Process

Along with clear, direct communication with health care professionals, family caregivers need to be helped to “see what we see,” so they recognize for themselves the progressive deterioration of their loved one as signaling EOL (Forbes et al., 2000). RNs can help by discussing with family caregivers the indicators of the trajectory of dying (as discussed above), being careful to use clear, layperson language and avoid nursing jargon and acronyms. In addition, RNs should ensure all conversations with family caregivers about EOL use clear, unambiguous language, avoiding EOL euphemisms such as “not doing well,” “wearing out,” or “may not get better” (Hebert, Prigerson, et al., 2006).

Maintaining Close Contact with Family Caregivers

Once the EOL trajectory of a nursing home resident has been clearly communicated to family caregivers by the physician, RN, and other members of the health care team, it is crucial to maintain close contact with family caregivers. Discussions to prepare family members for the death of a nursing home resident should not be static or “one time only” (Hebert, Prigerson, et al., 2006). Because of the emotional and stressful nature of EOL conversations, discussions about EOL should occur in stages so family members can absorb and process the implications of the information. RNs and other health care professionals should not be surprised if family caregivers do not retain all of the information given at an EOL family conference. The RN should plan to follow up with family members and reiterate key information so it is made explicit and communicated clearly. Doing so will most likely avoid family members believing their loved one’s death was an unexpected and negative outcome of poor care (Oliver et al., 2006).

Misperceptions in Acceptance of the Dying Process or Preparedness for Death

Health care professionals may be surprised to learn that providing care for a nursing home resident, sometimes even for years, does not indicate that the family caregiver is aware of or prepared for the impending death of the resident (Herbert, Dang, & Schulz, 2006). Furthermore, family members may not perceive dementia symptoms as a terminal condition (Forbes et al., 2000). Many nurses have heard family members make remarks such as “I knew Mother’s mind was gone, but I didn’t think her body would give out yet.” In particular, “black caregivers, caregivers with less education, those with less income, and those with more depressive symptoms prior to the death were more likely to perceive themselves as ‘not at all prepared’” (Hebert, Dang, & Schulz, 2006, p. 683). RNs should be aware of the increased risk for complicated grief reaction in these family caregivers.

Re-evaluation of Routine Grief Support Initiatives

Routine grief support initiatives for family caregivers following the death of a nursing home resident should be carefully re-evaluated and possibly discontinued. Routine after-death bereavement support is no longer supported with empirical evidence, since it is ineffective and unnecessary for the vast majority of those who are bereaved (Kissane et al., 2006; Neimeyer, 2004; Schut & Stroebe, 2005; Zhang et al., 2006). In addition, routine bereavement support intervention (e.g., follow-up telephone calls to family members) is often scheduled in the days and weeks after the death of the nursing home resident, which is much too soon, as complicated grief reaction cannot be determined for at least 6 months (Neimeyer, 2004; Zhang et al., 2006).

Nursing homes, stretched for professional staff, should not allocate professional resources to after-death grief support programs but rather educate and encourage RNs to prepare family members in advance of the death of a nursing home resident, which is likely to be more beneficial (Hebert, Dang, & Schulz, 2006). For bereavement care of family members, providing grief support and referral for grief counseling to those who make contact to request it—rather than routinely offering bereavement support—is recommended (Schut & Stroebe, 2005).

Sending Sympathy Cards

After the death of a nursing home resident, sending a sympathy card signed by frontline care staff who knew the resident is still recommended. The nursing home administrator should ensure a supply of religious and secular sympathy cards are available to frontline care staff, as family members have indicated they value that staff members took the time to sign the card and include comments and remembrances about the resident (Davidson, 1999; Hutchinson, 1995). Anecdotally, family members have reported that a card “rubber stamped” by the nursing home administration was seen as uncaring and impersonal.

Acknowledgement that Nursing Homes Are De Facto Hospices

The nursing home industry does not view itself as caring for the dying nor as providing palliative care as a primary service, even though some 30% of nursing home residents die each year (Philips et al., 2006). On the contrary, “the formal message of
nursing homes is one of rehabilitation and maintenance of function” (Oliver et al., 2006, p. 194). Instruments such as the MDS, as well as nursing home regulations and policies, were developed in response to widespread concerns that nursing home residents were dying as a result of poor care. Nursing home funding, regulations, and policies are closely tied to rehabilitation and maintenance of function activities (Oliver et al., 2006).

The nursing home industry and regulatory bodies need to include palliative care in the primary role of nursing homes and not mandate that rehabilitation and maintenance of function are achievable or desirable for all nursing home residents (Oliver et al., 2006). Nursing home staff and professionals experience dissonance between conducting resident care in such a way as to meet regulatory requirements and achieve optimal funding for the nursing home and wanting to provide optimal palliative care for dying residents that does not include rehabilitation or inappropriate emphasis on maintenance of function (Porock & Oliver, 2007).

EVALUATION OF PROCESS AND OUTCOME FACTORS

The purpose of this evidence-based practice guideline is to provide guidelines for EOL support of family members before the death of a nursing home resident. Below, process and outcome indicators to evaluate implementation of the guideline are discussed.

Process Indicators

Process indicators are those interpersonal and environmental factors that can facilitate use of the guideline. One process factor that can be assessed with a sample of frontline staff, nurses, or physicians, is knowledge about family preparedness for death of a loved one and EOL support. The *Family Preparedness and End of Life Support Knowledge Assessment Test and Process Evaluation Monitor* are both available in the full guideline, with instructions for their use (Davidson, 2009). These tools can be administered to frontline staff, nurses, and physicians following staff development sessions on the use of the guideline to determine understanding and assess support for carrying out the guideline.

Outcome Indicators

Outcome indicators are those expected to change or improve with regular use of the guideline. With consistent application of this evidence-based practice guideline, the major outcome indicators that should be monitored over time are:

- Reduced or no complaints from family members that they felt unaware of and unprepared for the impending death of their loved one in the nursing home (Forbes et al., 2000; Hebert, Prigerson, et al., 2006).
- Reduced or no complaints from family members that they felt a lack of clear communication about the impending death of their loved one in the nursing home (Forbes et al., 2000; Hebert, Prigerson, et al., 2006).
- Positive feedback from family members that they had good communication with nursing home staff and the resident’s physician and believed the resident had a good death for which family members were well prepared.

CONCLUSION AND IMPLICATIONS FOR GERONTOLOGICAL NURSING PRACTICE

All family members and significant others with an attachment to a nursing home resident should have the opportunity to be prepared for the death of their loved one and to receive EOL support. Lack of preparedness for the death of a significant other has been clearly linked to complicated grief disorder (Barry et al., 2002; Hebert, Dang, & Schulz, 2006). Therefore, family caregivers of nursing home residents are likely to benefit from use of this evidence-based practice guideline. Preparing family members in advance of the death of a resident is a better use of scarce nursing home resources than after-death grief support initiatives. EOL training for nursing home staff and activities to educate and prepare family members for the death of a loved one were discussed in this article and are more fully detailed in the complete guideline (Davidson, 2009). Professional nurses must play a key role in enhancing efforts to support older adults at the EOL and their families.

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