Dementia, a devastating terminal disease, affects 5.2 million Americans and is estimated to grow to nearly 16 million by the year 2050 (Alzheimer’s Association, 2010). The course of dementia varies, but in the final stage, nearly half of all nursing home (NH) residents with the disease experience chewing or swallowing problems (Mitchell, Kiely, & Hamel, 2004). At this crossroads, faced with a decision about how best to feed their loved one, many families select tube feeding. Nationwide, the number of NH residents with feeding tubes is 6.5%, with the majority of those individuals having advanced dementia (Centers for Medicare & Medicaid Services, 2010).

Despite the notion that the tube will prolong life, research fails to demonstrate the benefit in this population. More than a decade ago, a seminal review documented that feeding tubes do not prolong survival, improve nutritional markers, or prevent aspiration or pressure ulcers, and are associated with significant complications (Finucane, Christmas, & Travis, 1999). These findings were reiterated in a more recent systematic review (Sampson, Candy, & Jones, 2009). If there is no benefit to this intervention for patients with advanced dementia, why are health care providers continuing to offer this option, and why are family members agreeing to have them inserted?

Likely, the reason is complex and multifactorial. Much of the extant research, using secondary analyses of large databases, found that tube feeding and advanced dementia is associated with individual patient, organizational, and financial factors. For example, non-White residents are significantly more likely to be tube fed than White NH residents (Mitchell, Teno, & Roy, 2003). NHs with full-time speech therapists on staff, fewer nursing assistants, and located in an urban setting are associated with higher rates (Gesbert, Mosier, Brown, & Frey, 2000). Research also suggests financial incentives exist for gastroenterologists, hospitals, and NHs (Teno et al., 2010).

Additional insight into the underlying reasons for the use of feeding tubes was produced by qualitative methods. We examined two NHs in a region of the country with overall high rates of feeding tube use (Lopez, Amella, Strumpf, Teno, & Mitchell, 2010). Using ethnographic methods, we found that organizational culture influences feeding decisions. A NH with a low tube-feeding rate focused on contextual issues including environmental modifications and empowering staff, whereas the NH with the high tube-feeding rate had an institution-like environment with less staffing at meals and misinformed staff.
Use familiar foods, flavors, and rituals as a means of remaining connected to the individual with dementia and maintaining their familial relationships.

ways to manage eating and feeding. Moreover, 39% reported a physician bias toward feeding tubes, and 13% “felt pressured” to insert a tube (Teno et al., 2011).

We propose an additional explanation for the continued use of feeding tubes. We believe that some family members turn to feeding tubes in the face of this devastating disease because they are not offered an acceptable alternative. Currently, decisions not to use feeding tubes are considered by some providers and families as a form of withholding treatment. The frequently used phrase comfort measures only implies that care is being limited or diminished. Likewise, the more recent term, comfort feeding only (Palecek et al., 2010), suggests that the quality of meals and assistance provided to those with advanced dementia will be limited or lessened in some fashion. Instead, we propose that family members be provided with

loved one. Mealtimes were crucial to maintaining personhood for the individual with dementia as well as for family caregivers. Applying the principles of intensive individualized comfort care to this larger view of mealtimes suggests that three components of mealtimes should be addressed within the context of meals as a shared experience: past, present, and future. Therefore, those implementing intensive individualized comfort care for mealtimes should encourage family members to provide information about food preferences, values and beliefs, and cultural background that can be used to create individualized meal plans. They should use familiar foods, flavors, and rituals as a means of remaining connected to the individual with dementia and maintaining their familial relationships, while little emphasis should be placed on weighing residents or counting calories. In the present, family members should be provided pragmatic strategies to assist in feeding and dealing with challenging behaviors during mealtimes. Finally, mealtimes should be used as a mode of assessing for anticipatory grief, validating painful emotions, and referring family members to support services.

Clearly, additional work is needed to operationalize the elements of intensive individualized comfort care using the best available evidence. Rather than “giving up,” choosing this paradigm of care should trigger a thorough assessment using standardized instruments, selection of interventions based on the highest level of evidence available, and continuous evaluation and revision of the care plan.

The need for high-quality end-of-life care for individuals with dementia will indeed grow. We propose that intensive individualized comfort care become the gold standard of care for those with advanced dementia. Family members should not be forced to “give up and let go,” withhold care, or accept a diminished form of care for their loved ones. Nurses must step to the forefront by creating, testing, and implementing intensive individualized comfort care strategies.

REFERENCES


home residents with severe and irreversible cognitive impairment. *Journal of the American Geriatrics Society*, 48, 1593-1602.


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The authors have disclosed no potential conflicts of interest, financial or otherwise. Dr. Amella acknowledges the support of grant R21AG032083 from the National Institute on Aging, National Institutes of Health, “Feeding the Elderly in Late-stage Dementia: The FIELD Trial.”

doi:10.3928/00989134-20120605-02