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Nurses' perspectives on feeding decisions for nursing home residents with advanced dementia

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Abstract

Aim—To develop a broad understanding of nursing beliefs, knowledge and roles in feeding decisions for nursing home residents with advanced dementia.

Background—Concern is growing about the common use of feeding tubes in nursing home residents with advanced dementia. Nurses can play an important role in providing information and guiding family members through difficult feeding decisions. Little is known about nurses' perspectives on feeding decisions.

Design—Qualitative descriptive.

Methods—In-depth semi-structured interviews of 11 licensed nurses who were experienced in caring for nursing home residents with dementia.

Results—Analysis of the interview transcripts revealed three themes: insufficient empirical information, ambiguous role in feeding decisions and uncertainty about moral agency in decisions about the placement of feeding tubes.

Conclusions—Despite views that family members would benefit from guidance in decisions regarding the placement of feeding tubes, nurses were, nevertheless, reluctant to become involved in these difficult decisions.

Relevance to clinical practice—If nurses are to guide family members in decisions about the use of feeding tubes, they need more education about evidence-based practice as well as support in exercising their nursing responsibilities.

Keywords

end-of-life decision-making; ethics; feeding tube; long-term care; qualitative study

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Contributions Study design: RPL, EJA, SLM, NES; data collection and analysis: RPL; manuscript central: RPL.

Conflict of interest The authors have no conflict of interest.

Introduction

Concern is growing about the use of feeding tubes in nursing home residents with advanced dementia, given very limited evidence for its benefits in this population (Finucane *et al.* 1999, Vollmann *et al.* 2000, Van der Steen *et al.* 2002, Volicer 2005 Arinzon *et al.* 2008). However, nationally, 18–33% of severely cognitively impaired nursing home residents have feeding tubes (Teno *et al.* 2002, Mitchell *et al.* 2003). Large differences, however, exist on state-by-state usage of feeding tubes, with some states as high as 44% (Teno *et al.* 2002). Nursing home nurses maintain primary responsibility for the nutritional care of residents, yet little is known about their perspectives on decisions to use feeding tubes. The purpose of this study was to develop a broad understanding of nurses' beliefs, knowledge and roles in feeding decisions for nursing home residents with advanced dementia.

Background

Dementia is a non-curable and increasingly common condition. Currently, nearly 30 million people worldwide have dementia (Wimo *et al.* 2007), and the number of people with this devastating illness is estimated to increase to 63 million by 2030 (Wimo *et al.* 2003). In the USA, over 5.2 million people have Alzheimer's disease and related dementias. Thirty per cent (30%) of those with dementia are living in nursing homes (Mitchell *et al.* 2005). Eating problems are typical in end-stage dementia (Amella 2004). Decrease in self-feeding abilities, together with eating and swallowing problems, results in an increased risk for malnutrition and weight loss, especially among those residing in nursing homes (Thomas *et al.* 2000).

Despite the lack of evidence for clinical benefit from feeding tubes, surrogate decision makers, most often family members, maintain a strong desire to 'do something' when food intake declines or feel a moral obligation to provide food and fluids (Mitchell & Lawson 1999, Finucane *et al.* 2007). Although surrogate decision makers in the US are encouraged to use advanced directives to guide decisions, these directives often do not provide specific guidance on hospitalisation, antibiotics, or artificial nutrition and hydration (Teno *et al.* 1997, Cohen-Mansfield 2008). Therefore, when faced with difficult decisions about feeding problems, surrogate decision makers frequently seek guidance from physicians and nurses (Mitchell & Lawson 1999, Forbes *et al.* 2000, Lopez 2007, 2009). While studies document physician characteristics and perspectives on such decisions (Shega *et al.* 2003, Modi *et al.* 2007, Bell *et al.* 2008, Hanson *et al.* 2008), less is known about the perspectives of nurses in nursing homes with regard to the placement of feeding tubes.

In a recent international literature review concerning decisions about artificial feeding in end-of-life care Bryon *et al.* (2008) identified 12 studies confirming that nurses had little direct influence on the decision-making process. Nurses did play an important indirect role in assessing residents' conditions, informing family and physicians about changes in health status and guiding family members through the decision-making process. Family members often asked nurses to assist them in clarifying and understanding information from physicians. The Bryon *et al.* review is limited, however, as it included artificial food and fluid administration in a variety of settings and with a variety of patient populations such as terminally ill, critically ill, those in persistent vegetative states, and severely disabled individuals. Few studies specifically address feeding tubes for those with advanced dementia, and none were conducted in US nursing homes. Thus, this study was undertaken to understand nursing beliefs, knowledge and roles in feeding decisions for nursing home residents with advanced dementia.

Methods

The parent study, from which this study is derived, explored individual and organisational level factors associated with feeding decisions for nursing home residents with advanced dementia in a region of the country with high usage of feeding tubes. Two nursing homes in southern USA were purposefully selected based on rates of usage. In this article, we specifically focus on data obtained from in-depth interviews with nurses to develop a broader understanding of feeding decisions for nursing home residents with advanced dementia.

Design

A qualitative descriptive design was used for data collection and analysis. Consistent with qualitative methods, sample size was not determined *a priori*; rather, participants were selected to obtain diverse perspectives and to provide a broad understanding of beliefs, knowledge and roles in feeding decisions for nursing home residents with advanced dementia. Data collection continued until theme saturation was reached and no new information was obtained (Strauss & Corbin 1998).

Setting and sample

A purposive sample of 11 licensed nurses (five RNs and six LPNs) was recruited in two nursing homes. Bed size was similar in both nursing homes (100–150). Eligibility criteria for participating nurses included 18 years or older, ability to speak English, willingness to participate in the study and at least six months experience in caring for nursing home residents with dementia. The sample was purposefully selected to include a wide variety of perspectives and experiences. Both RNs and LPNs were sampled because they have both frequent interaction and frequent communication with family members.

Data collection

The lead author (RPL) conducted the interviews. Participants were interviewed in a private location in the nursing home. Interviews were digitally recorded, along with written field notes of observations and thoughts immediately following the interviews, which ranged from 20–45 minutes. Interviews began with broad questions such as, 'Tell me about what is it like to feed residents with advanced dementia and what challenges do you face?' Thereafter, the researcher asked more focused questions such as, 'What happens when residents with dementia lose weight? Who makes decisions about hand feeding and feeding tubes? What role do you have in these decisions?'

Ethical considerations

The study was approved by the University of Pennsylvania Institutional Review Board and permission obtained from the administrators in each facility. Written informed consent was obtained from all study participants.

Data analysis

All recorded interviews were transcribed verbatim, checked for accuracy and imported into QSR Nvivo 8.0. Data were then analysed by the first author. The analysis involved an iterative process of description, analysis and interpretation, and three levels of coding (Wolcott 1994, Schreiber 2001). During first level coding, the researcher read the interviews line-by-line and assigned a code to each concept. In second level coding, similarities in concepts were identified and the codes collapsed into higher order categories. In third level coding, the categories were analysed to identify relationships between and among categories.

Several strategies were used to evaluate the quality of the study process and findings (Patton 1990, Mays & Pope 2000). An audit trail of research methods, sampling process and data analysis was maintained. Data sources were triangulated by interviewing nurses from two nursing homes, with different roles, points of view and education. In addition, the analysis was refined until the higher order categories could account for most cases, even those that initially appeared to be negative cases or deviant cases. Also, peer debriefing was conducted with co-authors. Finally, member checking was informally performed as the researcher validated impressions and preliminary findings with participants and allowed them to confirm, clarify, or offer additional information.

Results

Sample

Participants were all women with an average age of 44.4 (SD 12.5) and many years of experience (mean 21.3; SD 13.5). Most (10) participants were white, and one was African American. Ten participants identified themselves as Protestant and one was Catholic. There were five RNs (four Associate degree; one Bachelor of Science) and six LPNs.

Findings

Analysis revealed three major themes: insufficient empirical information, ambiguous role in feeding decisions and uncertainty about moral agency. Despite convictions that family members would benefit from guidance and support when making feeding decisions, nurses were nevertheless reluctant to be involved in these decisions. Instead, they assumed a neutral stance or used implicit forms of communication.

Insufficient empirical information—Most of the nurses, both RNs and LPNs, were unaware of empiric evidence concerning the risks and benefits of feeding tubes for nursing home residents with advanced dementia. Instead, when asked about the risks and benefits of feeding tubes, one RN said, 'Basically [regarding tube feedings] there's really no opinion because we can't give [family members] specifics. We can say, it may or may not help [but] there's just no way to really tell.' This nurse, like many others, was unaware that recent empirical evidence failed to demonstrate benefits of feeding tube use for people with advanced dementia.

In general, nurses overestimated the benefits of feeding tubes and underestimated risks. Most nurses viewed feeding tubes for residents with advanced dementia as an effective intervention to increase survival and 'keep residents alive.' One LPN commented, 'If they're not eating, the only way to keep them alive is by tube feeding them, no?' Only one nurse (RN) felt differently. She said:

Well I will tell you this, rest assured this tube may prolong the resident being here another week or so, but when you're going to die, you're going to die and there's nothing going to keep you here when it's time.

Many nurses also thought that feeding tubes improved residents' nutritional status. When asked about the benefits of feeding tubes for residents with advanced dementia, one RN responded, 'Total nutrition. Probably better nutrition than most people in the South eat. So the benefits would be an overall improvement of all systems.' One RN mentioned the convenience and ease of feeding and administering medications as another benefit of feeding tubes. She said:

At least you know how much hydration that they're getting and also it makes it easier ... they're going to get the therapeutic effect from their medication...yes you can feed them faster ...the biggest risk is aspiration pneumonia. Other than that, I haven't seen a whole lot of serious problems.

Few nurses thought that feeding tubes prevented or improved pressure ulcers, and only two nurses thought that they improved function. None of the nurses believed that feeding tubes prevented aspiration or improved residents' quality of life.

Ambiguous role in feeding decisions—Nurses described their role in feeding decisions as identifying weight loss, and then notifying the dietitian, speech therapist and doctor. When nursing home residents experienced significant weight loss, unresponsive to interventions such as assisted feeding, changes in diet consistency, appetite stimulant medications, or high calorie supplements, most nurses felt that family members should be offered the choice of placing a feeding tube. This was considered a difficult 'personal' decision that family members should make, keeping in mind the previously expressed preferences of residents.

The nurses' role was to facilitate communication between the doctor and family members concerning placement of a feeding tube, in common parlance, 'getting pegged.' One RN described the process this way:

If they continue not to eat and continue to go down, then there's a risk for skin breakdown. So we have to watch for skin breakdown and we'll bring the family in and the doctor and see where they stand. If there's a living will and all that, we can see if they would like them to be pegged or not.

Nurses, however, consistently reported that they were not to advise, guide, or influence family members in these decisions. One RN said, 'The way I answer them [family members] is [to say] we can't really be specific ... We tell them it's your decision, it's not ours; and we don't want to influence that.' Indeed, the taboo against advising family members was so strong that two RNs incorrectly reported that it was against the law for nurses to talk with family members about feeding decisions. Another RN said, 'We would discuss the options, not specifically. I think [it's] something to do with state [law] and you're not actually to say I would recommend or not recommend.'

Some nurses were uncomfortable talking with family members about feeding decisions. One LPN described her discomfort in this way:

I really don't feel comfortable talking, trying to persuade [family members] one way. I mean maybe I'd tell them about it. I haven't in the past. I probably should provide them with more information about it. But in the past, when I've talked to them and they've asked about it, I haven't wanted to present [information].

Nurses commonly believed that they should be neutral, unbiased observers with regard to any decisions. For example, one RN was asked about her responsibility in family meetings where feeding decisions were made. She said, 'I was there as a resource ... to listen ... to how they feel, and primarily I was asked to be there.' Nurses most often felt their role was only to report observations about residents. One LPN described, 'I just explain what I see because the social worker and [others] always explain it. [Family members] just want to hear what we have to say about what we saw and maybe the trouble we're having.' In addition, some nurses felt that their role was to support whatever decision family members made. An RN said, 'I can't change their mind[s], but I can just help them through their pain by just being there to comfort them, and that's all I can do, is just comfort them during their decision making and try to make them understand [that] whatever the decision, it's what they wanted and we'll support them in any way.'

Because nurses were fearful of expressing a 'personal opinion,' an implicit communication method was sometimes used, as with this LPN:

I'd rather not...just prolong their suffering. So I tend ...to say, well you know, your mom or [dad's] not able to do this, what quality of life does he or she have? They wouldn't want to be like [this] if they already have decreased skin integrity. You wouldn't want to put your mom through that or your father through that.

Another nurse described how a family might be subtly influenced to accept a feeding tube. She suggested that a nurse might say, 'Well you know we can put a tube in, and maybe your mother will feel better or we can feed her by a tube [when] she can't swallow anymore.'

Uncertainty about moral agency—Moral agency refers to individual responsibility for moral judgments and actions that comport with morality. The nurses in this study had limited awareness of the moral dimension of their nursing practice. They compartmentalised judgements about feeding tubes as 'personal opinion,' rather than a moral dimension of nursing care. This ambiguity in moral agency added to reluctance to advise family members about feeding decisions and further led to confusion over any responsibility or need to take action.

Several nurses described boundaries between personal self and professional self. When speaking as a 'person,' they felt empowered to confront difficult moral decisions associated with feeding tubes. As a nurse, however, they felt empowered only to talk about the risks associated with feeding tubes or to provide physical care. Knowledge of feeding options was compartmentalised as personal opinion rather than clinical judgment. One RN said, 'As a nurse, I would talk to them [families] about the risks, and as a person I would talk about the emotional part of it.' Another RN explained her dilemmas this way: 'Personally, with demented people, I don't like G- tubes. Of course, [as a nurse], it's just physical care and all the problems that go with having a tube in place.' Avoiding 'thinking like a nurse,' another RN said, 'Personally, as a person, not trying to think as a nurse, I know that [feeding tubes] are probably not going to improve [the resident's] quality of life.'

Discussion

Family members and surrogate decision makers deserve to be fully informed of all risks, benefits and burdens of feeding tubes. This is best accomplished by an interdisciplinary team approach where nurses should play a major role. Nurses are in an ideal position to guide and support families through the complex process of decision-making and have an obligation to provide clear and complete information (Eggenberger & Nelms 2004, Todd *et al.* 2005, Bryon *et al.* 2008). The findings of this study, however, suggest that nurses either retreated from decision-making or engaged in covert methods of communication owing to insecurity in three areas: knowledge of empirical data, role ambiguity and moral agency.

This study supports the work of others, including studies of nurses' roles in feeding decisions in the UK, Israel and Japan, where nurses also felt their roles in feeding decisions to be minor (Bryon *et al.* 2008). Much like nursing home nurses in the Netherlands, nurses in our study felt their primary role was to inform the doctor and family about the resident's condition (Pasman *et al.* 2004). Perception of a limited role in feeding decisions may be due in part to the long-term care setting or to amount of education. For example, a study of RNs with Bachelor of Nursing and Master of Science degrees in two large teaching hospitals in Canada found that most nurses used the word 'advocate' to describe their roles, and thus provided and answered questions about all aspects of feeding decisions (Todd *et al.* 2005).

Our study supports previous research demonstrating the need to educate nursing home nurses about palliative and end-of-life care, and specifically about feeding problems in advanced dementia (Gibbs 1995, Raudonis *et al.* 2002). Although there have been several educational initiatives to enhance geriatric nurses' knowledge and skills about end-of-life care (Ersek *et al.* 2006, Kelly *et al.* 2008), this study suggests that many more nurses are in need of further

education in this area. It extends these findings by suggesting that providing empirically based information about feeding tubes may not be enough. Nurses also need clarification about their role in feeding decisions and legitimate authority to engage skilfully as a member of an interdisciplinary team dedicated to informing and supporting family members in feeding decisions.

The American Nurses' Association (ANA) position statement on foregoing nutrition and hydration states that withholding artificial nutrition and hydration is a decision to be made by the patient or surrogate along with the healthcare team. As members of the healthcare team, professional nurses (RNs) are obligated to participate in the process. Preparation of nurses in effective communication skills related to complex decisions made by patients and families, especially those with an ethical or moral overlay, could be improved in most schools of nursing. LPNs, on the other hand, are not trained nor can they be expected to have the body of knowledge needed for such communication. Nonetheless, they are often the only nurses readily available to families in nursing homes. Therefore, support from RNs is essential.

Insufficient empirical knowledge of risk and benefits of feeding tubes is not unique to nurses. Shega *et al.* (2003) surveyed more than 400 doctors and found that they, much like the nurses in this study, overestimated the benefits of feeding tubes for people with advanced dementia. Most nurses, owing to their clinical experience, recognised that feeding tubes failed to prevent aspiration or improve residents' quality of life. Nurses compartmentalised this knowledge, however, as 'personal opinion' rather than expert clinical judgment. By denying this important moral dimension of nursing practice, they failed to recognise how, as nurses, they could act and intervene to support family members in making informed decisions. This is consistent with Rubin's (1996) study of experienced nurses who, nevertheless, failed to achieve an expert level of nursing practice. Much like nurses in this study, they deferred responsibility for clinical decisions, did not consider the benefit achievable through their efforts, and consistently attributed responsibility for their decisions to others. Additional work is needed to explore strategies that would empower nursing home nurses to value and apply their clinical expertise to the benefit of residents and family members.

Limitations

The views of the nurses in this study may not be reflective of nurses in other settings or parts of the country. Those who chose to participate could have been self-selecting; however, a variety of perspectives were represented in the data indicating that a range of opinions were obtained. The small homogenous sample was derived from one part of the country, and conclusions cannot be drawn about how backgrounds, ethnicity and demographics of the participants influenced their perspectives. Moreover, data were collected and analysed by one researcher; however, all authors weighed the meaning of the findings. Furthermore, the rich and vivid perspectives offered by these nurses are informative to clinicians, nursing home administrators and future researchers.

Conclusions

The findings suggest that despite views that family members would benefit from guidance in decisions regarding the placement of feeding tubes, nurses are nevertheless reluctant to get involved in these difficult decisions. The findings of this study highlight the challenges inherent in developing better ways to support family members during feeding decisions. A major challenge will be creating professional nursing environments in nursing homes, along with policies and practices that support expert ethical and clinical judgment by nurses as members of an interdisciplinary team.

Relevance to clinical practice

When making end-of-life decisions for nursing home residents, family members seek guidance from knowledgeable health care providers, including nurses (Lopez 2007, 2009). Strategies to enhance nursing capacity to counsel family members about feeding decisions must meet three criteria: (1) nursing homes must have at their disposal up to date research evidence and best practices related to feeding residents with advanced dementia; (2) nurses' roles in feeding decisions, along with the interdisciplinary team, must be clear; and (3) expert nurses must be made more available in long-term care.

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