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Active Patient and family involvement with patient care in the ICU: Survey of critical care nurses

Girling WB and Magdi M R

Center for Research & Innovation in Medical Education, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

***Corresponding Author:** Magdi M **R**, Center for Research & Innovation in Medical Education, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

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Abstract

Objective: Family caregiver involvement may improve patient and family outcomes in the intensive care unit. This study describes critical care nurses' approaches to involving family caregivers in direct patient care.

Research Methodology/Design: This is a qualitative content analysis of text captured through an electronic survey.

Setting: A convenience sample of 374 critical care nurses in the United States who were subscribers to one of the American Association of Critical Care Nurses social media sites or electronic newsletters.

Main Outcome Measure: Critical care nurses' responses to five open-ended questions about their approaches to family involvement in direct patient care.

Findings: Nurse, patient, and family caregiver factors intersected in the context of the professional practice environment and the available resources for family care. Two main themes were identified: "Involving Family Caregivers in Patient Care in the ICU Requires Careful Assessment" and "There are Barriers and Facilitators to Caregiver Involvement in Patient Care in the ICU."

Conclusion: Patient care demands, the professional practice environment, and a lack of resources for families hindered nursing family caregiver involvement. Greater attention to these barriers as they relate to family caregiver involvement and clinical outcomes should be a priority in future research.

Keywords: Caregiver; Critical Care; Engagement; ICU; Involvement; Family; Patient Care

INTRODUCTION

As technology advances, patients, families, and providers face increasingly complex issues regarding end-of-life decision making. Over the past several decades many patients and their families have demanded increased control over and participation in decision making at the end of life. A patient's right to self-determination is the moral underpinning of these demands. However, patient self-determination in practice is complex. Advance directives (AD) were thought of as one way for patients to ensure their wishes would be followed in the event the patient was no longer able to participate in decision making. Nevertheless, decision making near the end of life often is still regarded as problematic even with advance directives. There are discrepancies between the treatments patients receive and those they had indicated they preferred via AD, usually with patients receiving more curative or aggressive types of treatment than desired (Connors et al., 1995; Teno, Licks et al., 1997; Teno, Lynn et al., 1997).

Concerns about the level of treatment received are not unique to patients and families. In a survey of physicians (n=687) and nurses (n=759), Solomon et al. (1993) reported that 78% of house staff and 58% of attending physicians reported sometimes offering treatments that were overly burdensome to their patients. Most providers were more concerned about overtreatment than undertreatment.

Based on the results of a grounded-theory study of intensive care unit nurses, house staff, and attendings (n=21), Simmonds (1996) reported that all providers interviewed agreed that extreme treatment or overtreatment often occurred in the intensive care unit. The providers identified fears of litigation and the unrealistic expectations of family members as the main reasons for overtreatment. Providers also did not "blame families entirely for their unrealistic expectations" (Simmonds, p. 171), citing unrealistic providers and unclear communication between providers and families regarding the implications of treatment decisions as part of the reason families chose more aggressive treatment.

Other researchers examining the relationship-between seriously ill cancer patients' predictions of their own prognosis and their treatment preferences found that patients' beliefs about prognoses were associated with their treatment choices (Weeks et al., 1998). Patients were more optimistic about their 6-month survival than their physicians and were more likely to choose life-extending therapy over comfort care. The researchers suggested that enhanced communication between physicians and patients about prognosis would improve clinical care.

The need for improved communication among providers, patients, and families near the end of life of a patient is a common finding of several studies (Norton & Talerico, 2000; Tilden, Tolle, Garland, & Nelson, 1995; Wilson & Daley, 1999). Problems with communication regarding end-of-life decision making include lack of information, lack of access to providers, and lack of family inclusion in the process of decision making (Kayser-Jones, 1995). Problems with communication may make it difficult for patients or families to make informed choices and for providers to honor patients' wishes.

Few researchers have explored how patienttreatment decisions change over the course of an illness or how patients, families, and providers achieve agreement on treatment decisions. Tilden, Tolle, Nelson, Thompson, & Eggman (1999) described four typical phases that surrogate decision makers go through when coming to a decision to withdraw life support for their loved one: recognizing futility; coming to terms; shouldering the surrogate role; and facing the withdrawal question. Based on data from a 14-site participant observation study, Degner and Beaton (1987) described four patterns of control over the decision-making process: provider, patient, family, and jointly controlled. In provider and jointly controlled decision making, providers used both formal and informal strategies designed to influence patients' or proxies' decisions near the end of life.

More recently, Markson et al. (1997) reported that the vast majority (91%) of 653 physicians surveyed would attempt to persuade a patient to change a decision assessed to be ill-informed, and most (88%) would attempt to persuade a patient to change a decision seen by providers as medically unreasonable or in conflict with that patient's best interest.

Several researchers have examined how providers attempt to persuade the patient (Kayser-Jones, 1995; Sullivan, Hebert, Logan, O'Connor, & McNeely, 1996; Zussman, 1992). One group of researchers described how physician providers (n=14) attempted to frame the decisions regarding mechanical ventilation and intubation to patients with end-stage chronic obstructive pulmonary disease (COPD). All but one physician admitted to framing information presented to patients in such away as to influence the patient's choice (Sullivan et al.).

The purpose of this study was to develop a grounded theory of how decisions were negotiated among providers and family members near the end of a patient's life. During the development of the theory, Reconciling Decisions Near the End of Life, identification was made of several strategies providers used to assist patients and families to shift from curative to palliative treatment choices and goals. These strategies are the focus of this article.

Method

Following institutional review board approval, provider participants were recruited via a letter of invitation (which received a 60% positive response rate), and family members were recruited via church bulletins. The sample consisted of 20 participants (10 nurses, 5 physicians, and 5 family members) from a midsize Midwestern city. Only data from the nurse and physician participants are presented in this article. Of the 15 providers, 12 were women and 3 were men (see Table 1 for additional characteristics of the provider sample).

A grounded-theory research design was used for this study (Glaser, 1992; Glaser & Strauss, 1967; Strauss, 1987). There were 18 provider interviews. Each provider was interviewed once; three providers were interviewed a second time to facilitate member checks. All interviews, which were conducted at a time and place of participant convenience, were tape-recorded and transcribed verbatim. The first four interviews were conducted using open-ended questions and lasted 60–90 min. Later interviews lasted 30–60 min, with questions becoming increasingly focused on the evolving categories as data analysis progressed (see Table 2 for examples of early and later interview questions).

Consistent with a grounded theory research design, data were analyzed using open coding, constant comparative analysis, and axial coding (Glaser, 1992; Strauss, 1987). Dimensional analysis was used as an adjunct data analysis tool. Dimensional analysis is a systematic inquiry into the "parts, attributes, interconnections, context, processes, and implications" of a phenomenon (Schatzman, 1991, p. 309). Following each interview, extensive analysis was done, theoretical questions were raised, and questions were developed for subsequent interviews.

Analysis of the first three interviews (all nurses) revealed that they engaged in a host of strategies that were directed at assessing how patients understand their situations. This included assessing whether the patient's understanding was similar to that of the health care provider (e.g., whether it was "realistic" from the provider's perspective) and whether decisions patients made seemed "reasonable" from the nurses' perspectives. Analysis of these initial interviews also revealed that providers engaged in a host of strategies aimed at assisting patients in coming to a more realistic understanding of their situations and in making more reasonable decisions. Although these strategies could be viewed as paternalistic, they also offered an opportunity to explore these issues in greater depth. Subsequent interviews were designed to gain an understanding of what the providers were doing, what was directing their assessments as well as their efforts to alter patient perceptions, and whether these strategies changed over time.

Deliberate theoretical sampling of providers who did and did not engage in these strategies was not possible because there was no way to make this distinction before interviewing. Therefore, theoretical sampling was built into the design of the interviews. This was accomplished by adding questions to the interviews that would identify whether the provider participant engaged in such assessments and perspective-altering strategies and would explore how they understood these actions and what they were trying to accomplish.

Common to all those who described such strategies was a goal of either preventing a "bad death" or hoping to achieve a "good death." Providers who were concerned about how realistic the patient's understanding was described the relationship between the patient's understanding, the decisions that resulted from that understanding, and the consequences of those decisions for the quality of their death.

This analysis raised the question of what these providers actually meant by the good death that they were trying to achieve and the bad death they were trying to avoid. Interview questions were altered to enhance understanding of these notions and to understand the relationship between being-realistic and these two possible outcomes. Analysis of the subsequent interviews (as well as reanalyzing previous interviews) revealed that these providers had experiences with patients whose unrealistic understandings led to burdensome treatment decisions and thus to deaths with unnecessary pain, suffering, overly aggressive treatment, and unresolved family issues. At this point a theoretical decision was made to pursue an understanding of the processes of shifting goals and treatment decisions.

Subsequent theoretical sampling was designed to discover whether any predictable or patterned differences existed among provider types (e.g., nurses and physicians), work settings (e.g., acute or home care), and work experience (e.g., experienced or novice). It was hypothesized that these might explain which providers or what conditions were likely to result in a provider engaging in strategies to achieve a good death or avoid a bad one and which were not. Further exploration of this relationship in subsequent interviews suggested that experience with dying patients was common to providers who were concerned about and organized their strategies around quality of death. Experience itself, however, did not necessarily lead to such an approach. Additional theoretical sampling was done in order to provide some comparisons around length of experience as a health care provider and, in particular, with patients who were dying.

Several procedures were integrated into the methodological design of this study to maximize the credibility of the results (Guba & Lincoln, 1989; Strauss, 1987). All interviews were transcribed verbatim, checked for accuracy, and entered into a computer software program designed to assist qualitative data management (QSR NUD*IST 4, 1997). Memos and matrices were used to track the evolving theory and the methodological choices made by the researcher during the study. The principal researcher met weekly with a multi-disciplinary grounded theory dimensional analysis group. The researcher was engaged in data collection and analysis for 22 months, but the majority of the data was collected during the first 16 months. Analysis and member checks continued until the study was completed. Member checks were ongoing throughout the study and included second interviews with three provider participants (chosen for the breadth and depth of their experience), fieldwork, and interactive presentations of findings to small groups of providers similar to those who participated.

Results

This section begins with a brief synopsis of the grounded theory of reconciling decisions near the end of life (Norton, 1999), which provides the con-

Reconciling Decisions Near the End of Life

Health care providers often described knowing a patient's death was imminent before the patient or family knew. When these providers believed a patient's death was near, they shifted the purpose of their interventions toward helping the patient achieve a good death. With that in mind, providers worked toward changing patients' and families' treatment decisions from what providers believed were unrealistic curative choices to more realistic palliative choices. In this context, unrealistic decisions were those intended to cure, and realistic decisions were those intended solely to palliate symptoms or to forego curative treatments.

Providers reported that when patients or families continued to make unrealistic (curative) treatment decisions near the end of life, the patient would probably not experience a good death, possibly even having a bad one. A good death was characterized by all providers in a similar way as one that includes time to resolve personal business, time to reconnect with family, time to forgive and be forgiven, time to achieve important goals, and time to say good-bye to loved ones, while maintaining good pain and symptom control. A difficult or bad death was characterized by not being able to say good-bye; having unfinished business, unresolved conflict and anger, and difficulty grieving; undergoing futile treatment, creating bad memories for the family; and having poor symptom and pain control.

According to providers, changing the patient's or proxy's understanding, that is, their "big picture," to one in accord with the providers' assessment led the patient and family to realistic goals and thus to palliative treatment choices. From the providers' perspective, the big picture was a gestalt of the patient's condition constructed from information about the diagnosis, test results, prognosis, general assessment findings (including physical, emotional, and spiritual factors), treatment options, treatment efficacy, treatment burdens, and patient goals. This information, filtered through providers' knowledge, insights, and experience, formed providers' overall picture of what was going on with the patient. In this context it was the big picture, as perceived by providers, that determined whether goals and treatment decisions were realistic.

Providers expressed a belief that understanding the big picture would probably lead to realistic decisions that in turn would lead to a good death. On the other hand, lack of understanding or acceptance of the big picture increased the likelihood of making unrealistic treatment decisions that would result in unnecessary pain and suffering and in missed opportunities for a good death (e.g., not being able to say good-bye to loved ones). Providers often imputed a lack of understanding and/or acceptance of the overall big picture as the cause of patients' or proxies' adherence to unrealistic goals. Unrealistic goals were goals that the patients could not achieve and/or that led to burdensome aggressive treatments that made it difficult, if not impossible, for patients to achieve a good death. One provider described a dying patient who wanted to continue chemotherapy:

This patient was described as having an angry and bitter death. The provider was frustrated by the patient's unwillingness to accept a realistic big picture and her continued adherence to curative treatment decisions. It is the provider big picture that providers said must be shared by patients and family members in order for them to make realistic decisions. Therefore, changing the patient's big picture became the focus of provider interactions.

Providers responded differently to perceived unrealistic patient or proxy goals. These responses included: (a) avoiding interactions with the patient and family, (b) referring the patient and family to another provider, and (c) using strategies aimed at shifting patients' unrealistic goals and treatment decisions to more realistic ones. Providers' often responded to unrealistic patient or proxy goals and decisions by using strategies to shift the patient or family picture, and to increase their understanding of what was happening. Early on these strategies were intended to "lay the groundwork" for a new picture. Laying the groundwork was typically followed by strategies focused on shifting the patient or family to a new picture. Finally, once a patient had shifted to a new, more realistic picture, provider strategies focused on helping the patient and the patient's family to accept and keep that realistic picture. Once a patient and family accepted a new picture, their treatment decisions were most likely to be palliative and thus more likely to ultimately result in a good death (Fig. 1). The individual strategies presented in the following sections are grouped under general purposes. However, most strategies were used for more than one purpose (e.g., teaching could be used to lay the groundwork, to shift the understanding of a patient or family toward the patient's picture, and/or to help the patient or family accept a new picture).

Providers' perspectives are presented here. The intent was not to imply that only one picture exists, that all providers share one picture, or even that there is such a thing as an accurate picture. Rather, the intent was to illustrate providers' behaviors when they conclude that the patient or proxy does not have an accurate big picture.

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