Intensive Care Nurses’ and Physicians’ Experiences With Demands for Treatment: Some Implications for Clinical Practice

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Objective: This study was conducted to develop an empiric description of intensive care unit (ICU) physicians’ and nurses’ (participants) experiences providing life-sustaining treatments at the insistence of family members, treatments that they believed should have been withheld or withdrawn. From this description, steps to minimize or prevent their sources of distress in such situations are suggested.

Design: Semistructured, open-ended interviews. Participants were asked to describe cases in which treatment had been provided primarily in response to demands from family members.

Participants: Six physicians and 6 nurses from 6 university-affiliated ICUs in Canada. All were members of a task force developing a multicenter policy to address demands for treatment, and physician members were heads of their ICUs.

Outcome Measures: Systematic analysis of interview transcripts and synthesis of findings.

Results: Participants recalled 28 cases in which treatment had been provided at the insistence of family members. Many cases described were very distressing for both medical staff and family members. Consistently problematic areas included: (1) suffering of dying patients, (2) the marked distress of family members, and (3) a breakdown in the relationship between care providers and families.

Conclusions: Conflict with family members about decisions to limit life-sustaining treatment can be very stressful for health care providers. Three important areas that give rise to distress were identified in this study. These key sources of distress should be looked for. They could be addressed by: (1) identifying to family members the importance of minimizing suffering and ongoing bodily injury of patients at risk for dying, (2) by doing so addressing directly the distress of family members by the provision of emotional support, and when appropriate directed toward helping them accept that the patient is dying, and (3) pursuing efforts to maintain or create a good relationship with family members despite disagreement about the appropriateness of continuing life-sustaining treatment.

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In 1996, a multidisciplinary task force, representing 6 university-affiliated intensive care units (ICUs) in a large Canadian urban center, was formed to address ethical issues in intensive care. By consensus, a mandate was reached to create policy to address demands for treatment believed by clinicians to be futile or inappropriate. The problem of demands was perceived by this group to be the most important ethical problem faced at that time. We took this opportunity to explore the experience of providing treatment owing to demands from family members, hoping to uncover in part the reasons why this experience was seen as so problematic.

Intensive care staff frequently decide that life-sustaining treatment should be withdrawn or withheld (limited).1-7 When patients or proxies persistently disagree and demand treatment, “futility” disputes are created.8 Such conflicts can be protracted9 and distressing for both ICU staff and family members.9

Initial attempts to limit the requirement to provide treatment described specific situations, such as providing intensive care to patients in persistent vegetative states,10-12 as futile. Treatment that has less than a 1% chance of success, or that will never end dependence on intensive care, has been labeled as futile and, it was suggested, need not be provided.13,14 Others have argued that the standard of care delineates the requirement to provide treatment.15,16 More recently, policies have provided procedural mechanisms to resolve17,18 or prevent such disputes. Although the futility movement has now waned, the requirement for physicians to talk to family members about limiting treatment remains as a fundamental requirement.19

Factors that influence ICU physicians’ and nurses’ decisions to withdraw or withhold treatment have been described20 as has the process by which withdrawal is negotiated with families.21

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This research was performed while Dr. Workman was a MSc student in the Institute of Medical Science at the University of Toronto.

Supported in part by a fellowship from the University of Toronto Department of Medicine (S.W.), and by a Canadian Institutes of Health Research Investigator award (P.A.S.).

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Journal of Critical Care, Vol 18, No 1 (March), 2003: pp 17-24
The experiences of nurses\textsuperscript{22} and physicians\textsuperscript{23} withholding and withdrawing life-sustaining treatment also have been examined. However, to our knowledge no study has attempted to determine why the provision of futile treatment can be such a difficult problem for medical personnel. Therefore, we obtained first-person narrative accounts of futile treatment to better understand this experience from the perspective of medical staff. From the essential features described by participants in this study, we propose several approaches to manage difficult aspects of demands for treatment.

METHODS

Design

ICU physicians and nurses from 6 ICUs were asked to relate their experiences providing treatment that they felt should have been withdrawn, but that was provided at the insistence of family members. The rationale for using narrative data to obtain a rich and complete description of a complex phenomenon has been described previously.\textsuperscript{24} This study was approved by the University of Toronto Committee on Use of Human Subjects.

Setting

Participants were recruited from a 5-hospital task force representing 6 ICUs. The mandate of the task force was to create policy to address demands for treatment in ICUs (the policy was completed and may be viewed: http://www.utoronto.ca/jcb/Resources/ccm_policy.htm). A description of the development of the policy was published recently in January 2001.\textsuperscript{25} The primary researcher and interviewer (S.W.) was a member of the task force and a general internist who was working at the time in an ICU not affiliated with the task force.

Sample

The sample consisted of one ICU director (physician) and one nurse from each of the 6 ICUs. One of the units was a pediatric ICU. All participants had ongoing research and policy exposure to the topic as well as first-hand experience. Participants had between 5 and 25 years of experience in an ICU. The physicians were men, the nurses were women.

Data Collection

Participants were asked to describe cases in which they had provided life-sustaining treatment at the insistence of family member(s), treatment that they felt should not have been provided. Interviews were conducted by the primary researcher in private at the ICU or in physician’s offices. Participants recalled from 1 to 5 cases each for 28 cases in total. Four cases were ongoing at the time of the interview. Interviews ranged from 60 to 90 minutes duration and were transcribed verbatim.

Data Analysis

Data were analyzed in 5 steps. First, each interview was read through to become familiar with the text. Second, each interview was coded with identification of thoughts, feelings, and actions, in keeping with a previously described method for examining accounts of moral experience.\textsuperscript{26} Third, common themes were developed for each interview by comparing the compiled thoughts, feelings, and actions. Next, comparison between interviews allowed the development of the common themes presented in this study. Finally, the coded transcripts of physicians were compared with those of nurses, although the small sample size limits the use of this comparison.

The validity of the findings was enhanced in 4 ways. First physician and nurse participants were recruited from 6 ICUs, allowing multiple perspectives of the phenomenon to be sampled. Second, the themes and the raw data that gave rise to their development were presented to the 3 co-authors (P.A.S., P.M., W.H.) for confirmation. However, the data were not analyzed independently by each. Third, participants were provided with an opportunity to review and comment on the results section of this article. All read them and none felt that their experiences were being misrepresented. Finally, although the subject of the interviews was predetermined, to minimize interviewer bias, participants were allowed to describe at length the experiences they found most relevant.

RESULTS

Participants described difficult cases involving dying patients whose distraught relatives demanded treatment be continued or initiated. Physicians and nurses voiced similar accounts and had similar concerns, consistent with a prior study that examined the ethical concerns of intensive care staff.\textsuperscript{27} Representative and succinct quotes, chosen by the principal author, are included for each of the 3 main sources of concern described by participants: (1) the suffering of dying patients, (2) distressed family members, and (3) a breakdown in the relationship with family members. Quotes from nurses are followed by “RN,” quotes from physicians by “MD.” The number of nurses and physicians who made statements supporting each of the themes also is provided.

Dying Patients (4 MDs, 6 RNs)

The suffering of dying patients, as indicated by pain behavior and/or ongoing injury such as ischemic limb necrosis, was very distressing for nurses and physicians. Although symptom control was provided in response to pain behavior, ongoing bodily injury also was problematic. Two nurses noted that if family members were unaware of the extent or severity of injuries, revealing the body of the patient could result in their accepting the necessity to withdraw treatment.

“The patient was slowly losing blood pressure and was developing necrosis, gangrene of the extremities, upper and lower...The death took at
least a good 3 weeks. And I was thinking I could never do this to my parents, to any of my family members, to any human being...Nurses would not want to care for this patient, they would leave, literally, crying about how bad this was.” (MD)

“Even the one day there was myself and one of the other nurses, she—we turned him and I said, ‘You know, maybe if we show this daughter his back, you know, maybe she doesn’t realize what we’re talking about here; maybe she’s never seen that his back is necrotic and he’s rotting in the bed here.’” (RN)

**Distressed Family Members and Prognostic Uncertainty (6 MDs, 6 RNs)**

The distress of the family members of dying patients was witnessed by both nurses and physicians and was, in fact, a significant cause of distress for the nurses and physicians in this study. Some family members sometimes struggled very painfully with the decision to limit treatment.

“One family member made the decision to withdraw treatment, and the other just could not accept it. I have this life-long sense that we had failed them, that we may have irreversibly damaged the relationship between them.” (RN)

“I think it’s one of the hardest things I have ever seen in my entire life. It [prolonged treatment] causes a lot of pain for the families. You know where they are coming from, [in wanting treatment continued] you feel very strongly for them. It would be so nice to stop because we know how it is going to end. [With the death of the patient].” (RN)

“I can’t imagine the anguish of a parent, or how they would come to utter the words of, you know...’I agree to what you are saying. (about withdrawing treatment).’”

**A Breakdown in the Relationship With Family Members (4 MDs, 5 RNs)**

Loss of trust in physicians and a very difficult relationship with family members was described.

“The family actually threatened the physician who was caring for this patient. They said that they would charge him with murder should the patient deteriorate. And that if we didn’t resuscitate the patient, they would charge us with murder. Very unpleasant, incredible tension of course. .Finally I said the ‘D’ word [dying]. .And it was like, ‘Oh? No one told us that before.’” (MD)

“Sometimes talking with families about treatment withdrawal, I ask myself ‘Am I a monster?’ Because the questioning and the attitude of some families [about withdrawing treatment] really makes me wonder if I am perceived as a monster, as if I am trying to kill their loved one.” (MD)

“It was very accusatory. They [the family members] were afraid if you asked them to leave the room that you would try to bump the patient off. That’s how paranoid and accusatory this family was.” (RN)

**DISCUSSION**

The physician and nurse participants in this study described similar sources of concern and distress arising when family members would not allow life-sustaining treatments to be limited. We suggest that in situations of conflict, or potential conflict, each of these areas be considered by medical personnel. Each of the 3 areas of concern is discussed later, and some practical suggestions to address them are provided.

**Patient Suffering**

Unrelieved suffering of patients was very distressing for medical personnel. Identifying and communicating the strongly felt obligation to prevent suffering and respect the bodily integrity of patients could create a shared mandate to pursue patient well-being as an important goal separate from curing the patient. Because, “In intensive care settings, goals seldom follow a strict dichotomy between cure and palliation,” an early emphasis on comfort is appropriate. Participants in this study described a strongly felt obligation to minimize or prevent ongoing injury to the bodies of patients thought to be dying. This obligation also could be discussed with family members, perhaps as part of comfort care.

**Distressed Family Members and Prognostic Uncertainty**

Some family members were described to be extremely distressed. Explaining to family members that prolonged treatment and decisions to withdraw treatment can be very difficult could help create a supportive relationship and allow issues of emotional support to be more openly addressed. Some family members suffered severe emotional distress while considering decisions to limit treatment and heated conflict within families was de-
scribed, although death was felt to be inevitable by health care providers. Because futile treatment has been defined as treatment that will “only prolong the final stages of the dying process,”15 and because treatment frequently is withdrawn because the patient is dying,29 it is puzzling to us that only one participant described explaining to family members that the patient was dying. Of course such discussions may have occurred and not been related by participants, but we thought it unusual that such an important aspect of the decision-making process was not described more frequently. (Only one participant described a case in which demands for treatment arose when there was agreement between medical personnel and family members that the patient was dying, and the conflict was neither heated nor prolonged.) For these reasons, we wonder if it is possible that failure to obtain prognostic consensus caused or exacerbated some conflicts. Because of the small sample size and design of this study, further research to determine how often and effectively that a terminal prognosis is conveyed to family members before discussions about treatment withdrawal occur would be necessary to better understand these results.

Breakdown in Relationship With Family Members

A severe breakdown in the relationship between ICU staff and family members was very upsetting. Descriptions of family members accusing health care providers of trying to kill the patient showed that some health care providers were perceived to be acting in bad faith. Clarifying and separating capabilities from intentions could help mitigate such perceptions. (“We want, as you do, to make your loved one better, but lack the ability to do so.”) The negotiation literature shows that simply meeting demands for treatment will not improve strained relationships, and that specific efforts to build or maintain a good relationship with family members must be identified and pursued.30 If trust already has begun to be lost, simple statements and questions such as, ‘I am concerned you don’t trust us. Why? What can we do to help?’ could be useful to start the process of relationship rebuilding. One physician suggested that finding a health care provider who is trusted also was useful.

Limitations

This article has 3 main limitations. First, it was conducted with a small select sample of experienced nurses and physicians who perceived conflict over limiting treatment to be an important problem. Their views and experiences may not represent the majority and the information they provided about the experience of family members is clearly second hand. Second, participants were from a homogeneous environment, all were from Canadian tertiary care academic ICUs in a city with a very high (>90%) ICU occupancy rate. Finally, empiric studies examining the experience of treatment withdrawal from the perspective of family members are lacking and the experience of family members was not examined directly. One recent study has shown that conflict between ICU staff and family members is perceived commonly by family members.31

CONCLUSIONS

The nurses and physicians who participated in this study described conflict arising from conflict over decisions to limit treatment to be very distressing, especially when the patient was perceived to be suffering, or there was a breakdown in the relationship with distraught family members. By highlighting these 3 areas of concern, this empiric study allowed steps directed at conflict over limiting treatment to be addressed more fully and methodically. As a first step, in situations of conflict or potential conflict, physicians and members of the health care team should ask themselves 3 questions:

1. Has the importance of ensuring patient comfort and maintaining the patient’s bodily integrity been examined and discussed with family members?
2. Are family members extremely distressed? Do they require more emotional support? If so, has prognostic consensus been reached, or is the possibility of treatment withdrawal distressing because family members believe that survival remains possible?
3. Has there been a breakdown in the relationship between family members and medical personnel? What steps, besides providing treatment, can be taken to address this breakdown.

Addressing these questions before initiating or
continuing discussion about limiting treatment could help health care providers to address, if not resolve, these sources of their distress. Reducing caregiver distress could create an environment more conducive to fully addressing decisions to limit treatment and to the provision of compassionate end-of-life care.

REFERENCES