

Respiratory Therapists' Experiences and Attitudes Regarding Terminal Extubations and End-of-Life Care

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BACKGROUND: Respiratory therapists (RTs) routinely care for patients with life-limiting illnesses and in some hospitals are responsible for terminal extubations. Data on how such experiences affect RTs are scarce. The objective of this work was to survey RTs at 2 academic medical centers about their experiences caring for patients with terminal extubations. **METHODS:** An online survey was distributed to the hospitals' RTs. Survey data included demographics and experiences with end-of-life care and terminal extubations. The survey was derived from previously published questionnaires plus input from hospital RT leaders. **RESULTS:** Sixty-five of 173 RTs (37.6%) responded. Of these, 42.4% were ≥ 50 y old, and 62.7% were female. 20.3% had ≤ 5 y experience; 52.5% had ≥ 16 y. 93.8% self-reported being involved in at least one terminal extubation; of those, 36.1% reported performing ≥ 20 . Nearly half (47.5%) wanted to be involved in family meetings discussing terminal extubations, but just 6.6% were frequently involved. Only 32.3% felt that they received adequate education regarding terminal illness in RT school; 32.3% reported gathering this knowledge while working. 60.0% wanted more formal education around terminal patient care. 27.9% reported sometimes being uncomfortable with performing a terminal extubation; most of these rarely felt that they had the option not to perform the extubation. **CONCLUSIONS:** RTs are rarely involved in end-of-life discussions despite a desire to be, and they experience situations that generate discomfort. There is demand for more formal RT training around care for terminal patients. Clinical protocols that involve RTs in meetings before ventilator withdrawal should be considered. *Key words:* palliative care; respiratory therapist; ventilator; end of life. [Respir Care 2016;61(7):891–896. © 2016 Daedalus Enterprises]

Introduction

The number of people who die in the ICU as a result of withdrawal of life-sustaining therapy is increasing.¹ However, as the SUPPORT study demonstrated nearly 20 y ago, physicians would often offer life-sustaining therapy

for a longer time to their patients than they would have chosen for themselves.² In recognition of this, more critical care teams are having informed discussions with patients and their surrogates about compassionate discontinuation of life support in cases with poor prognosis or impaired quality of life.

The procedure to withdraw ventilator support has been described in critical care and palliative care to ensure patient and provider comfort.^{3–5} The decision to withdraw ventilator support, however, is one that involves extensive discussion between the critical care team and patient surrogates. It requires melding the patient's values and goals

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with the medical team's expert recommendations regarding the severity and expected prognosis of the illness.⁶ Involvement of key stakeholders, such as palliative care practitioners, to, for example, aid communication with families or direct careful titration of medications is becoming part of the end-of-life care algorithm.⁵ In all cases, the process demands introspection and readiness on the part of all involved. It has long been suggested that improved

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communication among providers, defined chiefly as physicians and nurses, can reduce the degree of discomfort around withdrawal of life-sustaining therapy.^{7,8} However, the care provider often called upon to perform the removal of ventilatory support itself, the respiratory therapist (RT), is often entirely excluded from the preparatory communications and crucial goals-of-care discussions. As a result, RTs, when compared with registered nurses, rate the dying process less favorably and see greater need for improvement.⁹ Therefore, when called to perform a terminal extubation, RTs may be more likely to experience distress.

RTs provide ubiquitous support and expert management of respiratory illness throughout a patient's hospital course. This care intensifies when mechanical ventilation is required, and the therapist becomes a vital member of the critical care team.¹⁰ The role of the therapist with patients receiving life support is to maintain the airway, to ensure the safe function of the life support equipment, and to act as a technical and clinical consultant member of the health-care team.

RTs develop strong relationships with the patients for whom they provide care, just as registered nurses, physicians, and other providers do. Nonetheless, when the decision is made to withdraw ventilatory support, the RT is rarely included in that discussion.¹¹ Exclusion from the opportunity to discuss and understand decisions to remove artificial, life-sustaining technology and how care will proceed afterward creates the potential for anxiety and moral distress if the perception on the part of the RT is that he or she is having a direct hand in the patient's death by removing ventilatory support. Furthermore, many RTs have not received adequate end-of-life care education as part of their training.¹⁰ This, too, can lead to discomfort and unwillingness to perform these procedures.

There is a dearth of studies on these issues. Although there are many studies that examine physicians' and nurses' viewpoints on end-of-life care,¹² there are few that address those of RTs. In a 2005 survey of RTs at 6 southern California hospitals, Willms and Brewer¹¹ found that 73% of RTs surveyed in their study wanted to be a part of the conference that led to a decision to terminally extubate,

QUICK LOOK

Current knowledge

There is increased focus on end-of-life care and the difficult decisions that are often made in regard to removal of life-sustaining therapy, such as mechanical ventilation. Respiratory therapists (RTs) are key health-care providers in these critical situations, yet there is little attention paid to the quality of their experiences when involved in terminal extubations.

What this paper contributes to our knowledge

Our survey revealed that most RTs desire further training regarding end-of-life care and would welcome inclusion in the discussions involving removal of ventilator support. Focused end-of-life education and involvement in the care plan can help to alleviate any distress on the part of the RT when asked to perform a terminal extubation.

13% felt some degree of moral or ethical distress at having performed the extubation, and fewer than half received education on termination of life support in RT school or while working. Another study on RT perceptions on the withdrawal of life support in the intensive care unit that solicited open-ended reflections found a strong desire for increased inclusion and collaboration with the teams taking care of patients at the end of life.⁹ Our literature review found scant data on the extent of communication that RTs have with the medical team and families around removal of ventilatory support, their perceptions of the patient's comfort and symptom burden post-withdrawal, or their desire for additional education in end-of-life issues.

Our objective was to understand the experiences of RTs as they relate to performing terminal extubations, including whether and how they were included in the decision-making process and the degree to which they communicated with families about the process of removal. We also queried the frequency and degree of moral distress, their desire for more formal training in the care of patients at the end of life, and their comfort with how patients' symptoms are managed post-withdrawal.

Methods

Setting and Sample

We surveyed RTs at 2 large urban academic medical centers part of the same health-care system in the southeast. All RTs practicing at either hospital at the time of the

Table 1. Respondent Demographics

Characteristics	n (%)
Age, y	
18–30	13 (20.3)
31–49	22 (37.3)
≥50	25 (42.4)
Female sex	37 (62.7)
Education, highest degree	
Associate/diploma/certificate	13 (20.0)
Bachelor’s	22 (33.8)
Master’s or higher	4 (6.2)
Unknown	26 (40.0)
Experience (total), y	
1–5	12 (20.3)
6–15	16 (27.1)
≥16	31 (52.5)
Experience (current site), y	
1–5	17 (28.8)
6–15	18 (30.5)
≥16	24 (40.7)
Involved in a terminal extubation	61 (93.8)

n = 59.

survey were included; there were no exclusion criteria. The hospitals have a combined 14 critical care units with 149 beds and approximately 600–700 deaths/y. One hospital also includes a level III neonatal critical care unit and 4 hyperbaric oxygen units. After providing a description of our work to the Emory University institutional review board, we were told that our project was not considered human subject research, and our institutional review board declined to review the project.

Data Collection

The survey was distributed via e-mail lists of RTs at each hospital. Survey questions encompassed RTs’ knowledge, attitudes, and experiences regarding end-of-life care generally and terminal extubations specifically as well as demographics of the respondents (age, sex, degree, and years of experience Table 1). Respondents were typically asked to answer questions using one of two 5-category scales: never/rarely/sometimes/frequently/always or strongly disagree/disagree/neutral/agree/strongly agree.

To improve response rates, we kept the survey brief, made responses anonymous, utilized repeated outreach from RT leaders to publicize and distribute the survey, and provided an ample time frame for RTs to complete the survey (1 month). We secured responses from 65 of the 173 therapists (37.6%) working across both facilities. Demographic information was missing from 6 of 65 RTs (9.2%). Four of 65 RTs (6.2%) did not indicate experience

with terminal extubations and were excluded from analyses of relevant questions.

The research team assessed face validity by involving experienced RTs and RT leaders in the development of the survey. Many questions were based on a previously published survey of RTs on end-of-life care.¹¹

Data Analysis

We calculated descriptive statistics (proportions) for each question. To simplify presentation, we collapsed categorical questions with more than 2 answers into 2 or 3 relevant categories. All analyses were performed in SAS (SAS Institute, Cary, North Carolina).

Results

Sixty-five of 173 RTs (37.6%) responded to the survey. Of these 42.4% were ≥50 y old, and 67.2% were female. 52.5% had >15 y of experience as an RT, and 93.8% indicated participating in at least one terminal extubation (Table 1).

Communication

Of the respondents, 43.1% would like to have been included in team discussions with family about end-of-life issues (Table 2); this figure was 47.5% when the goal of the meeting was to discuss withdrawal of ventilator support (Table 3). Only 10.8% (Table 2) and 6.6% (Table 3) were frequently or always included in these discussions, respectively. Nearly 30% feel comfortable discussing end-of-life issues with patients or families on their own, but only 12.3% reported frequently doing so (Table 2).

Comfort and Moral Distress

Seventy-two percent frequently or always felt comfortable performing a terminal extubation (Table 3). If they did express discomfort, only 39.3% felt that there was frequently or always an available option to decline the extubation (Table 3). 65.6% felt that the patient’s symptoms were frequently or always adequately managed following the extubation (Table 2).

Education

Twenty-one respondents (32.3%) reported receiving sufficient education regarding terminal illness in respiratory school, and the same number reported gaining this experience during their working respiratory careers. A majority (60.0%) desired more formal education regarding the care of terminal patients (Table 2). 29.2%

RT EXPERIENCES WITH TERMINAL EXTUBATION

Table 2. Knowledge, Attitudes, and Experiences in General End-of-Life Care

Questions (Responses)	n (%)
Participation in end-of-life discussions	
I speak with my terminal patients and/or their families one-on-one about end-of-life care. (Frequently/Always)	8 (12.3)
I am part of the multidisciplinary medical team that discusses end-of-life care with a patient and/or family. (Frequently/Always)	7 (10.8)
I am comfortable discussing end-of-life care with a patient and/or family on a one-on-one basis. (Agree/Strongly Agree)	19 (29.2)
I would like to be included in multidisciplinary medical team meetings with a patient and/or family regarding end of life discussions. (Agree/Strongly Agree)	28 (43.1)
Education about end-of-life care	
I had sufficient education/training regarding terminal illness while I was in respiratory school. (Agree/Strongly Agree)	21 (32.3)
I have had sufficient education/training regarding terminal illness during my working respiratory career. (Agree/Strongly Agree)	21 (32.3)
I would like to have more formal education and support regarding the care of terminal patients. (Agree/Strongly Agree)	39 (60.0)
Symptom management at the end of life	
I am comfortable with the medical team's use of opiates for alleviation of dyspnea in terminal patients. (Agree/Strongly Agree)	47 (72.3)
I feel that the patient's symptoms are adequately managed [post-extubation]. (Frequently/Always)	40 (65.6)

N = 65.

Table 3. Knowledge, Attitudes, and Experiences in Terminal Extubations

Questions and Responses	n (%)
How many terminal extubations have you been involved in?	
1–5	10 (16.4)
6–20	29 (47.5)
≥21	22 (36.1)
Attitudes toward terminal extubations	
I feel comfortable with the decision to terminally extubate. (Frequently/Always)	43 (70.5)
I feel comfortable performing the extubations (Frequently/Always)	44 (72.1)
I feel comfortable with the family's presence during the patient's extubation and subsequent care. (Frequently/Always)	31 (50.8)
It is my preference that the MD perform the extubation. (Frequently/Always)	9 (14.8)
Experiences with terminal extubations	
I am given the option NOT to perform the extubation if I do not feel comfortable. (Always/Frequently)	24 (39.3)
The physician is present at the time of extubation. (Frequently/Always)	16 (26.2)
The physician performs the extubation. (Frequently/Always)	1 (1.6)
Communication around terminal extubations	
I am involved in the discussion with family about withdrawal of support. (Frequently/Always)	4 (6.6)
I would like to be included in family meetings where decisions to remove ventilator support are discussed. (Agree/Strongly Agree)	29 (47.5)
When I am involved in a terminal extubation, someone from the treatment team communicates with me directly regarding process of withdrawal. (Frequently/Always)	41 (67.2)

n = 61.

currently feel comfortable discussing end-of-life issues on their own with patients or families (Table 2). This figure was 34.5% for those reporting sufficient education on terminal illnesses in school or on the job and 25.0% for those who did not; a similar gap (33.3% vs 27.2%) was found for those reporting sufficient education in respiratory school.

The proportion reporting sufficient education in respiratory school varies substantially, depending on how long ago they were schooled: 41.7% if they have practiced 1–5 y, 43.8% if they have practiced 6–15 y, and 25.8% if they have practiced ≥16 y. The relationship is reversed for

self-reported sufficient education on the job: 33.3% if they have practiced 1–5 y, 25.0% if they have practiced 6–15 y, and 38.7% if they have practiced ≥16 y.

Discussion

As the presence of palliative care in the in-patient setting grows, it is vital that we consider broadening our view of what constitutes the interdisciplinary team. The increasingly complex hospital environment requires the expertise of many supportive services, such as physical therapists, speech therapists, nutritionists, and RTs, to name a few.

All of these disciplines can have an impact on the decisions made by patients and families facing an end-of-life issue and the type of care they choose to receive. Because of the increasing number of patients with serious illnesses necessitating life-sustaining therapies with removal after time-limited trials, we wanted to focus on the experiences of RTs who are on the front line of caring for these patients. Whether RTs should perform this activity is an open question whose answer varies by facility, but the resources available (in particular, the variable and often limited access to palliative care) necessitate their involvement. They need to be adequately prepared to perform these procedures in a way that minimizes stress and maximizes comfort for the patient, family, and therapist.

As our results suggest, many RTs feel comfortable performing these procedures, but in cases where there is a degree of ethical or moral distress, a majority perceive that they have little alternative option. This suggests a degree of moral distress for which there is little outlet for the practitioner. The long-term ramifications of this unease have yet to be fully explored.

Over a third of RTs reported that symptoms were not frequently or always well-controlled postextubation. Because RTs may often be alone or with a critical care nurse at the bedside, this is not only distressing to patients and families but to the RT as well, who cannot administer comfort medications beyond oxygen and respiratory therapy treatments (such as aerosolized treatments). This may also add to the unease surrounding the terminal extubation procedure.

Strategies to minimize distress can be developed. One way to potentially reduce the incidence of discomfort is to involve RTs in family meetings where the withdrawal of ventilator support is discussed as well as having them present for planning the technical, pharmacologic, spiritual, and social support available for the patient and family before and after the removal of ventilatory support. Although nearly half of RTs reported wanting to be involved in these discussions, in reality, only 6–10% reported being involved frequently. A better understanding of how this decision came to be, including a sense of the patient's goals of care and perception of quality of life, is paramount to conducting the care plan without unease. These structured family meetings could also serve as a model for how RTs can conduct the delicate conversations at the bedside. It would also be a way to communicate with the RT about what symptoms to expect and the team's symptom management plan, potentially decreasing moral distress.

Surveyed RTs also did not feel that they had received adequate education or training in end-of-life care; this is reflected in the 70% who did not feel comfortable discussing these issues on their own, the 63% who did not feel they received sufficient education regarding terminal ill-

nesses either in school or on the job, and the 60% who desired more formal education in caring for terminal patients. Encouragingly, the proportion reporting sufficient education in school was higher among RTs who have been in practice for fewer years (ie, went to school more recently), but still a majority of those in practice ≤ 5 y reported insufficient education on these topics in respiratory school. Unsurprisingly, the proportion reporting sufficient education on the job rose with more experience. Overall, the percentage reporting sufficient education either in school *or* on the job did not vary depending on how long they have been in practice.

The study has several strengths. Our survey built upon Willms and Brewer's initial work¹¹ and largely verified the findings of their survey in a different population of RTs at 2 academic medical centers in the southeast while asking a broader range of questions that included actual RT involvement in team meetings and the desire for additional education. It received a large number of responses, >90% of which were complete, from RTs with diverse ages and experiences. It is innovative in that it provided data on an understudied population, including the first data we are aware of on the frequency of RT involvement in terminal extubations, goals-of-care discussions, and their preference for additional education in terminal illness.

Study limitations include the fact that all RTs were within a single health-care system, limiting generalizability. Our data do not represent national estimates for RT distress in terminal extubations. We used the term "terminal extubation" in our study but did not specify the removal of patients from ventilatory support, such as bi-level positive airway pressure or noninvasive ventilation, leading to potential underreporting of end-of-life experiences for RTs. The survey is purely descriptive, and the research team did not ask about specific interventions that might improve the RT experience in terminal extubations. Future work may include the development and assessment of interventions, such as targeted education efforts and more intentional inclusion of RTs in critical care team meetings, to see whether this can alleviate the discomfort surrounding terminal extubations.

In a larger sense, our practice as palliative care providers should strive to include other care team members in end-of-life education and care implementation. The ethical and emotional burdens of caring for patients at the end of life can affect all care providers, but allowing the opportunity to truly understand the patient's unique goals and how that informs the decision making process will help to ease this burden and may even make this work more fulfilling for all.

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