# An Intervention to Improve Respiratory Therapists' Comfort With End-of-Life Care

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BACKGROUND: Respiratory therapists (RTs) are often involved in treating seriously ill and dying patients, but receive little instruction in end-of-life care. Prompted by several difficult cases, we developed an interdisciplinary program to introduce practicing RTs to ethical and end-of-life issues, and evaluated the program with a dedicated survey instrument. METHODS: A convenience sample of RTs from a university hospital and nearby community hospitals participated in a one-day interactive program, in 2005 (n = 49) and in 2008 (n = 36), that included role-play and didactic components. The questionnaire completed before and after the program included scales on comfort with end-of-life care and role in end-of-life care, and knowledge indices. RESULTS: Nearly all the RTs had recently encountered end-of-life situations, yet most had not received dedicated training and felt ill-prepared to deal with these situations; one third reported distress related to withdrawal of treatment. The 78 participants who completed both the before and after surveys had increased comfort with end-of-life care (P < .001) and their perception of their role in end-of-life care (P < .001). Knowledge about end-of-life care also increased (P < .001). CONCLUSIONS: A one-day interactive educational intervention can improve short-term RT comfort and role perception concerning end-of-life care. Evaluation of longer-term clinical outcomes and implementation in other **venues is needed.** Key words: respiratory care; medical ethics; death and dying; education; palliative care. [Respir Care 2010;55(7):858-865. © 2010 Daedalus Enterprises]

#### Introduction

Respiratory therapists (RTs) are integral to the care provided to hospitalized patients. While the RT's role is largely collaborative, they often treat patients alone and develop close working relationships with patients and families. RTs

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provide services to the sickest patients in the hospital. Because three quarters of RTs work in hospital settings, and largely in intensive care units,<sup>1</sup> they are heavily exposed to end-of-life issues. Nearly every RT has at some time removed a ventilator in the process of termination of life-sustaining treatment.<sup>2</sup> Furthermore, RTs spend a large amount of time with patients who are dying and, largely because they spend so much time at the bedside, they also interact substantially with the families of dying patients.<sup>3</sup> Almost no patient dies in a hospital without being cared for by an RT.

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Therefore, it is shocking that training concerning endof-life issues is not central to the education that RTs receive. The most common RT certification, RRT, requires 2 years of training and clinical experience. This training is heavily focused on technical expertise, and it is anticipated that the curriculum will become increasingly oriented in this direction with the progression of technology in mechanical ventilation and respiratory care.<sup>3,4</sup> Prior research suggests that less than half of all RTs receive education about termination of life support in their training.<sup>2,5</sup> Yet, without such training RTs are unlikely to develop the tools to help them deal with the issues surrounding dying patients and their families. Thus, RTs might be at risk of adverse effects, such as moral distress, depression, and burnout, from recurrent exposures to stressful circumstances without having an outlet to deal with these emotional and existential issues.<sup>6</sup> Consider the following case:

A one-year old girl had spent her entire life in the hospital, mostly in the intensive care unit. She was transferred to an academic medical center in hopes of receiving a liver transplant, but a series of complications, including sepsis, renal failure, pneumonia, and recurrent resuscitation efforts, left the child with a grim prognosis. All the clinicians agreed that this child would die and they were uncomfortable with the child's level of suffering as she continued to receive medical procedures.

However, the child's mother saw value in continued medical treatments. She saw a baby who responded to her holding and whose life had value, no matter how limited it was by chronic ventilation, blindness, deafness, dependence on dialysis and pressors, and continued neurological deterioration. While the child's mother acknowledged that the child suffered and would die, she felt that each moment of this child's life was precious. She was at the bedside constantly, helping the nurses to give meticulous care.

The mother was also indignant and able to tell you every error that had been made. She trusted few clinicians and felt that she was her daughter's only advocate. She studied every move that the healthcare team made and was quick to be critical. Despite acknowledging her child's prognosis, the mother wanted all available treatment and hoped that she could somehow survive.

RTs found themselves in a difficult situation as they attempted to provide aggressive treatment while worrying that they were causing suffering without potential benefit. The mother often criticized them for their technique and the suffering they caused, while continuing to demand fully aggressive care. The RTs were traumatized by the child's mother and by the effects of their efforts; they dreaded going to the bedside.

Because of this case and several other cases in which RTs encountered difficult interactions with dying patients and their families, a program was developed to enhance RTs' skills in handling end-of-life issues. We describe the one-day educational program and report its short-term effects on RTs.

# Methods

This study was performed at the Healthcare System Ethics Center at the University of California, Los Angeles

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The UCLA Health System Ethics Center worked with the UCLA Medical Center's Department of Respiratory Therapy to develop an educational program to improve RTs' abilities to assess and handle end-of-life treatment of hospitalized patients. We administered before and after questionnaires to the participants in order to evaluate the effect of the program. The educational program was conducted 3 times.

# **Educational Program**

The educational program aimed to be easily accessible to RTs and thus was conducted as a single full-day program on campus, near the hospital. RTs could use 8 hours of paid education time to attend the course. The underlying model included many of the components of previously suggested programs<sup>7,8</sup> and utilized experience and reflection, as was suggested by prior work.9 The program conceptualized that to provide end-of-life care a clinician must understand what happens physiologically when a person dies, be aware of the ethical issues related to end-of-life decision making and care, understand the elements of bereavement, understand hospital policy concerning withholding and withdrawing life-sustaining treatments, and practice interactions concerning end-of-life care in the hospital. Additionally, to address moral distress the program attempted to facilitate participant recall of experiences and recognition of emotional content, while fostering adaptive coping mechanisms based on group sharing and cognitive processing.<sup>10</sup> The curriculum was developed by the first author and involved a multidisciplinary faculty, including an ethicist, nurse expert in palliative care, social worker, child life specialist, spiritual care personnel, and physicians with specialties in critical care medicine, clinical ethics, geriatrics, and palliative care. In addition to didactic presentations, the interactive program included group discussions, discussion of cases, panel discussions, and role-playing (Table 1).

# **Participants**

RTs who participated in this program were volunteers who desired education in dealing with end-of-life issues among the patients they treat. All participants were RTs working in the in-patient ward and intensive care unit settings. The program was conducted 3 times, in 2 sessions in April 2005, and in one session in December 2008, when a large enough group of new potential participants had accumulated. The 2005 programs were attended exclusively by RTs from the UCLA Health System, whereas the

#### Table 1. Curriculum of Respiratory Therapist Education Program on End-of-Life Care\*

Care of the Dying

Principles of palliative care

Multiple stressors on families

Grief for patient and family

Fears of dying

Breaking bad news

Barriers to providing good end-of-life care (including personal and professional)

Interventions at the time of death for the patient and the family

Geriatrics

Common causes of death in the elderly

How treatment of the old and very old differs from routine adult care

Compression of morbidity

Special considerations in the geriatric population (eg, polypharmacy, dementia)

Advance care planning

Assessment and symptom management

Functional assessment

Child Development

Developmental considerations in children

Developmental tasks and stress variabilities

Stages of grief

What children know

Caring for a dying child

Facilitating coping through play

Sensitive approaches with siblings

Communicating with parents and children about death

Discontinuation of Mechanical Ventilation at End of Life, and Institutional Policies Concerning End-of-Life Care

The role of withholding and withdrawing life-sustaining treatment in in-patient care

The patient and family experience with death in the hospital

Withholding and withdrawing life-sustaining treatment

Ventilator withdrawal protocol

Techniques of ventilator withdrawal and terminal weaning models

#### Role Playing

Cases derived from participant experiences. Participants volunteered to assume the roles of patient, family members, and various members of the healthcare team, including the respiratory therapist. They enacted the scenes, took feedback, replayed interactions, and reflected on feelings derived from various communication styles and whether they were role-playing the patient, a family member, or a clinician role. Role-playing provided hands-on experience and insight into the effects of change in interaction style and the effects of collaborative care.

In the role-play concerning ventilator withdrawal, participants practiced a behavioral modification in which they paired with a team member (eg, nurse or physician) who knew the patient's family rather than entering the room alone.

#### Ethical Issues in End-of-Life Care

Models of ethical decision making in healthcare

Ethical principles and their application to the patient dying in the hospital

Advance care planning and decision making

Tools to facilitate end-of-life decision making and end-of-life decisions

Symptom management an ethical imperative

Principle of double effect, euthanasia, and assisted suicide

Legal and professional considerations

Medically inappropriate life-sustaining treatment

# Cultural Competence

Legacy of discrimination

Influences of cultural beliefs on palliative care

Factors influencing the individual's perspective

Comprehensive cultural assessment

Use of an interpreter

Individualized interventions

Communication skills to understand goals at the end of life

Cultural influences on decision making and patient values

Distrust of the medical system

Disparities in care

Special challenges and when cultures clash

Institutional applicability

#### Spiritual Issues

Spiritual model of care

Spiritual assessment of patients and families

Integrating spiritual issues into the treatment plan

Spiritual concerns at the end of life

Referrals for spiritual care

Role of religion and spirituality in death rituals, coping, and grief

Religion and spirituality in end of life decision making

Case Panel Discussion and Integration

<sup>\*</sup> The day-long program included lectures, interspersed with discussions, role-playing, and an opportunity for sharing experience and debriefing. Much of the learning occurred through discussion of cases

2008 program also included participants from nearby hospitals.

#### **Evaluation**

The participants completed a written survey instrument before the start of the program, and then again after the program. This instrument was developed to evaluate this program. Participants generated a unique code that they wrote on both the before and after surveys, so that the surveys could be anonymously linked. The evaluation protocol was approved as exempt by the UCLA institutional review board.

The survey instrument, in addition to basic descriptive information about the participant, included 3 sets of questions. One set of 4 items, newly developed for this survey, asked the participant about their level of comfort providing care to a patient at the end of life. The response options were on a 5-point scale that ranged from 1 = very uncomfortable to 5 = very comfortable. The 4 items formed a "comfort with end of life scale" with a Cronbach's alpha of 0.85.

Eight items asked participants about their attitudes concerning their personal role as an RT in end-of-life care. Topics included interacting with families and responsibility to participate in end-of-life care. The response options were on a 5-point that scale ranged from 1 = strongly disagree to 5 = strongly agree. Six of the attitude items (five of the items were reversed for directionality) formed a "role in end-of-life care scale" with a Cronbach's alpha of 0.75.

A set of 6 items was developed to evaluate participants' knowledge about respiratory symptoms at the end of life, treating the patient near death, information disclosure, and approach to a "difficult" parent. These true/false questions formed a "knowledge about end-of-life care index," computed by summing the number of correct responses and dividing by the number of questions answered. Participants who answered  $5 \ (n=8)$  and  $4 \ (n=2)$  knowledge items also were included in this before/after knowledge analysis. Finally, 7 items were asked about the UCLA Health System's policy on terminal weaning of mechanical ventilation, which was discussed as part of the program; these items composed a "ventilator-withdrawal protocol index." These latter items were completed only by UCLA RTs.

#### **Analysis**

First, participant descriptors were evaluated with frequencies and means. Because there were no statistically significant differences between these variables or among the comfort, role, or knowledge scores between the 2005 and 2008 groups, the analysis was performed together. To evaluate pre-intervention comfort, role, and knowledge, all participants were included. To evaluate the before/after

comparisons on the comfort, role, and knowledge items and scales, only participants who completed both the before and the after surveys were included, and matched paired *t* tests were used. Analysis was performed with statistics software (Stata 10, StataCorp, College Station, Texas).

#### **Results**

The 2005 programs included 49 participants and the 2008 program included 36 participants. The participants' mean age was 40 years, and 56% were female; they had a mean of 11 years (range < 1 y to 37 y) of respiratory therapy experience. There were no statistically significant differences between the 2005 and 2008 cohorts in these variables, prior training in end-of-life issues, or in their experience with dying patients, ethical distress, or withdrawal of life-sustaining treatment. (Table 2)

# **Baseline Education About and Experience With End**of-Life Care

Nearly all the respondents had been at the bedside when a patient died in the preceding 3 months, and 91% had participated in a ventilator withdrawal where death was expected. Thirty-five percent reported that they had experienced distress regarding withdrawal of life-sustaining treatment. Concerning education about death and dying, palliative care, or end-of-life care, 35% reported receiving education on these topics during a specific course in their respiratory therapy curriculum, and 59% recalled some informal coverage of these topics during respiratory therapy training (see Table 2). Whether an RT reported receiving education about death and dying issues was unrelated to the RT's age, sex, or years of experience (P > .3). Before the program, 31% agreed with the statement: "I received adequate education and training about end-of-life care."

## Participant Responses to the Program

Even before the program was conducted, RTs expressed gratitude for being recognized as a component of the team confronting difficult issues in caring for patients at the end of life. At the beginning of each program, feelings of isolation and of under-appreciation were apparent. The participants participated fully in consideration of cases, providing their personal examples and elaborating on each others' experiences. In the course of discussion, the depth of emotion and repressed burden of grief became apparent. Several explained that they had never had a chance to discuss these issues before, and others were unaware how affected they were by their prior experiences.

The role-play sessions were illuminating. Participants revealed that they felt like henchmen when they went into the room to discontinue a mechanical ventilator. Many described avoiding contact with a patient's family and

Table 2. Characteristics, Experience, and Education of the Respondents

	Full Sample	2005 Sample	2008 Sample*
Total	85	49	36
Female $(n, \%)$	48 (56)	29 (59)	19 (53)
Age (mean $\pm$ SD y)	$40 \pm 8$	$40 \pm 8$	$39 \pm 9$
Years as respiratory therapist (mean $\pm$ SD y)	$11 \pm 8$	$11 \pm 7$	$10 \pm 9$
University of California, Los Angeles staff (n, %)	71 (84)	49 (100)	22 (61)
Had had patients die while at bedside in last 3 months $(n, \%)$	83 (98)	48 (98)	35 (97)
Number of patients who died while at bedside in last 3 months (mean $\pm$ SD)	$2.4 \pm 2.5$	$2.7 \pm 2.8$	$2.0 \pm 1.9$
Experienced death of someone close in last 5 years (n, %)	70 (83)	44 (92)	26 (72)
Experienced distress over ethical issues about withdrawal of life-sustaining treatment $(n, \%)$	29 (35)	16 (34)	13 (36)
Participated in ventilator withdrawal where death was expected $(n, \%)$	77 (91)	46 (94)	31 (86)
Had education about death, dying, and palliative care in a specific course from respiratory therapist curriculum $(n, \%)$	29 (35)	16 (34)	13 (37)
Had education about death, dying, and palliative care in any part of respiratory therapist curriculum $(n, \%)$	48 (59)	27 (57)	21 (60)

<sup>\*</sup> There were no statistically significant differences (P < .05) between the 2005 and 2008 groups, except that 2005 group was composed of all University of California, Los Angeles staff.

hating the role of "extinguishing life." RTs imagined that families would not want to interact with them: during the role-play of discontinuing a ventilator, an RT with eyes cast down would "do the job" as quickly as possible and get out of the room as if carrying shame and dread. The role-plays were replete with tears and laughter.

During a scenario in which an RT was asked to remove a patient, who was expected to die, from the ventilator, he or she was encouraged not to enter the room alone to remove a ventilator of a patient who was unknown to them. The RT was encouraged to ask the nurse to introduce them to the family and to take a moment to meet each family member, thereby building a relationship and trust. The RTs found this to be a quite different experience. Other participants, who were playing the roles of patient, nurse, or family member also found the experience of the mock ventilator removal to be different when introductions and interactions came first. After the role-play, participants engaged in a lively and provocative debriefing, describing a large number of unrequited—and often never before revealed-end-of-life patient experiences that led to group learning and, for some, closure of difficult cases.

# Comfort, Role Perceptions, and Knowledge at Baseline

On the pre-intervention questionnaire, 64% of the participants were comfortable caring for a patient whose death was imminent, but only 29% were comfortable talking to patients who were near death, and to their families. Concerning the RT's role in end-of-life care, on the pre-inter-

vention questionnaire 58% of participants reported feeling that they were responsible for supporting the family during the dying process. Twenty-eight percent of the participants preferred not to be with a patient when he or she is dying, and 24% preferred that families not be around while they treated a patient. Eighty-three percent of the respondents disagreed with the statement "My job is strictly technical" (Table 3).

At baseline, the participants correctly answered 65% of the questions about end-of-life care relevant to RTs. About half of respondents recognized that Cheyne-Stokes respirations were not an indicator of suffering, about 60% were aware that a patient near death who pulls off her oxygen mask might be more comfortable without the mask, and a similar proportion recognized an appropriate approach to truth-telling at the end of life (Table 4).

Participants who reported receiving end-of-life education in the structure of a course evidenced higher baseline end-of-life capabilities. Participants who reported structured education, compared to those who did not, scored higher on the comfort with end-of-life care scale (3.71 vs 3.20, P=.01), on the role in end-of-life care scale (3.86 vs 3.55, P=.051), and on the knowledge index (70% vs 63%, P=.13), although only the comfort-scale scores were significantly different in this small sample.

# **Effect of the Education Intervention**

Of the 85 participants, 7 did not complete the postintervention questionnaire. Therefore, we compared the

Table 3. Attitudes About End-of-Life Care\*

	Pre-Test	Post-Test	P
Comfort With End-of-Life Care†			
How comfortable are you in caring for a patient who is imminently dying?	3.61	4.00	< .001
How comfortable are you in caring for a patient who will be withdrawn from the ventilator anticipating death?	3.46	3.95	< .001
How comfortable are you giving the healthcare team input about treatment decisions?	3.68	4.04	< .001
How comfortable are you talking to patients who are near death and to their families?	2.68	3.66	< .001
Comfort with end-of-life care (mean)	3.36	3.91	< .001
Respiratory Therapist's Role in End-of-Life Care†			
I am responsible for supporting the family during the dying process.	3.55	4.39	< .001
My job is strictly technical.‡	2.09	1.79	.01
I would prefer not to be with a patient when he or she is dying.‡	2.87	2.50	< .001
I am responsible for caring only for patients, not their families.‡	2.03	1.67	< .001
Sometimes I waste my time providing therapy to a patient who will not survive.‡	2.29	2.20	.40
I would prefer that families not be around when I am treating patients.‡	2.68	2.27	< .001
Respiratory therapist's role in end-of-life care (mean)	3.60	3.99	< .001

<sup>\* &</sup>quot; - 78

Table 4. Correct Responses on Knowledge Questions Before and After the End-of-Life Care Program\*

	Pre-Test (%)	Post-Test (%)	P
Cheyne-Stokes respirations at the end of life are not an indication of suffering.	45	79	< .001
Respiratory rate, $P_{O_2}$ , and blood-gas determinations may not correlate with feelings of breathlessness.	88	87	.80
Nothing I do will change how much an awake child suffers when suctioned.	75	84	.07
A patient near death keeps pulling off her oxygen mask. The patient may be more comfortable and experience less dyspnea if the oxygen is removed.	58	86	< .001
A patient from another culture is dying. The family demands that the patient not be told his prognosis. The patient has come to know you quite well. During a recent treatment, the patient asks, "Am I dying?" Following the family's wishes, you should reassure him that he is not. (For this question $n = 67$ .)	57	63	.29
A skilled respiratory therapist appropriately suctions a baby. The parent screams that the respiratory therapist is suctioning too aggressively and threatens to not allow him to care for the child again. The parent should be asked to leave the bedside during future suctioning.	63	86	< .001
Knowledge about end-of-life care index (mean)	65	81	< .001

pre-intervention and post-intervention questionnaires of 78 participants to evaluate the short-term effect of the intervention. On the comfort with end-of-life care scale, the mean increased from 3.36 on the pre-intervention questionnaire to 3.91 on the post-intervention questionnaire (P < .001 via paired t test, with the 1–5 scale in which 5 represented the most comfort). Among these scale items, the percentage of participants responding that they were

comfortable dealing with an imminently dying patient increased from 64% to 87%, and those reporting being comfortable talking with a patient near death and their family increased from 29% to 70%. The intervention also was associated with a significant improvement in the role in end-of-life care scale, with an increase from 3.60 to 3.99 (P < .001 via paired t test). The percentage of participants feeling responsible for supporting the family increased from

 $<sup>\</sup>dagger$  The questions about comfort with end-of-life care were on a 1–5 scale in which 1 = very uncomfortable and 5 = very comfortable. The questions about the respiratory therapist's role in end-of-life care were on a 1–5 scale in which 1 = strongly disagree and 5 = strongly agree.

<sup>‡</sup> Item reversed in computing scale score.

Table 5. Correct Responses on Knowledge Questions About UCLA Ventilator-Withdrawal Protocol Before and After the End-of-Life Care Program\*

	Pre-Test (%)	Post-Test (%)	P
The patient must have a no-cardiopulmonary-resuscitation order.	90	97	.10
The patient must have an expected survival of $\leq 72$ h.	81	78	.50
The patient must not be awake and alert.	76	78	.70
Upward titration of the opiate must be justified by documentation of symptoms.	64	75	.11
The patient must have a written advance directive indicating no heroic measures.	29	34	.37
Unlike PRN (as needed) orders, the dose and interval of opiate titration need not be specified.	25	37	.007
Paralytic agents should be withdrawn, if at all possible, prior to ventilator withdrawal.	59	86	< .001
Ventilator withdrawal protocol index (mean)	61	69	< .001
* n = 59.			

58% to 98%, and the percentage who would prefer that families not be around while they treated patients decreased from 24% to 13% (see Table 3).

The knowledge about end-of-life care index increased from 65% before the intervention to 81% after the intervention (P < .001) (see Table 4). An additional survey question stated: "If possible, it is better for patients to die from other causes (such as withdrawal of dialysis or medications) than to withdraw the ventilator, allowing a respiratory death." Whereas, 64% agreed with this statement on the pre-intervention questionnaire, only 37% agreed after the program. Knowledge concerning the UCLA ventilator-withdrawal protocol also increased after the intervention (61% vs 69%, P < .001) (Table 5)

# **Qualitative Response to the Program**

Many RTs revealed after the program that the experience was transformative. On the post-intervention questionnaire one commented: "It is so difficult to balance compassion and our professionalism. It's nice to know that I am not the only one who feels grief over my job sometimes."

Months after one of the seminars, a program participant was asked to remove the ventilator when expecting the death of a terminally ill homeless man whose out-of-state family could not be present. The RT asked that the chaplain be called. Although the patient was unknown to her and barely responsive, the RT held the patient's hand and spoke with him: "We are going to remove the tube in your throat; we know it has been irritating, and we are going to let you breathe on your own. You may feel some gagging and cough initially, but I will stay with you and make sure you are com-

fortable. Your family knows you are here and they are thinking of you." After ensuring that there were adequate orders for titration of medication should the patient experience dyspnea, and after waiting for the chaplain to arrive, the RT removed the ventilator and then continued to interact with the patient as she suctioned him. The patient died within a short period of time. The RT revealed that she approached a patient's death very differently after having participated in the program and was empowered to be a contributing member of the healthcare team. The RT and the nurse recognized that their actions honored not only the patient and his death, but their own part in the process—a window of acknowledgment of the heartache and suffering that clings to them in their work.

## Discussion

This study demonstrates that RTs encounter substantial end-of-life care, and a substantial minority expressed stress related to dealing with death and dying, which confirms the findings of prior evaluations.<sup>2,5,11</sup> In the context of this program, a much larger proportion of participants evidenced discomfort and stress related to dealing with patients approaching death, and their families. An interprofessional, collaborative interactive one-day program aimed to educate and address end-of-life issues demonstrated a substantial impact on RTs' knowledge, comfort, and role perception concerning end-of-life care.

Despite the fact that RTs are heavily exposed to endof-life situations, they reported being ill-prepared to deal with these issues. The intervention described in this paper might be broadly applicable for on-the-job RTs in a variety of settings where care is provided to seriously ill patients. The program might help RTs develop the additional skills to function at advanced levels in patient care so that they play a larger role in caring for the increasingly complex in-patient.<sup>12</sup> Whereas continuing education classes for the practicing RT have primarily focused on physiology, technology, safety and disease processes, this intervention suggests that end-of-life and palliative care are valuable additional topics for such coursework.

This study is limited by its small scope and short-term outcomes. The intervention was conducted with a convenience sample of 85 RTs who worked at several facilities in one region. These RTs are not necessarily representative of those practicing in the area or elsewhere; the program may have appealed to those with a greater interest in end-of-life care, which would make the findings of discomfort at baseline even more concerning. Nearly 10% did not have before/after data available. Longer-term and behavioral outcomes of the intervention are needed.

#### **Conclusions**

The substantial short-term success demonstrated by this program suggests that it should be tested in other venues and that additional evaluation of its impact is needed, including the effect on patients and families and the potential for decreasing burnout and turnover of RTs. The program is not resource-intensive and can be practically implemented in the context of in-patient care. These findings also suggest that greater emphasis should be placed on death and dying issues during respiratory therapy training.

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