

Effect of end-of-life care education on perceived self-efficacy of the pediatric respiratory therapist

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Background: End-of-life care (EoLC) is difficult for respiratory therapists (RTs), causing struggles with providing EoLC and grief during and after the death.

Objective: The objective of the study was to determine if EoLC education can increase RTs' perception of knowledge of EoLC, respiratory therapy as a valuable EoLC service, comfort providing EoLC, and knowledge of ways to deal with grief.

Methods: One hundred and thirty pediatric RTs completed a 1 h EoLC education session. Afterwards, a single-centre descriptive survey was administered to the 60 volunteers out of the 130 attendees. To determine RTs' self-rated change in knowledge of EoLC, perception of respiratory therapy as a valuable EoLC service, comfort with EoLC, and knowledge of ways to cope with grief. Statistical analysis included percent change.

Results: Overall, 96% of surveyed RTs agree they had an increase in knowledge, perception of RT services, comfort with providing care, and coping. Only 4% felt that this course had little benefit overall but still perceived value in RT EoLC and increased knowledge of long- and short-term ways to deal with grief.

Conclusion: Education on EoLC practices increased pediatric RTs' perception of knowledge, perceived value of respiratory therapy in EoLC, comfort with EoLC, and knowledge of coping resources.

Key Words: *compassionate care; education; pediatrics; end of life; empathy; respiratory therapy; end-of-life care*

INTRODUCTION

Respiratory therapists (RTs) treat seriously ill and dying patients, but they receive little instruction in end-of-life care (EoLC) [1, 2]. The primary goal of hospital medicine is patient survival, but as goals shift from restorative to EoLC, the transition can be difficult for hospital practitioners who find it challenging to provide EoLC [3]. Ethical concepts create a foundation for EoLC [4, 5] and emphasize there is no distinction between withholding and withdrawing treatments, yet more than 50% of medical professionals disagree. Staff report that fear of hastening a death is secondary in their actions of administering care [6]. RTs are asked to discontinue life-sustaining therapy for patients nearing death, such as removal of ventilation [7]. EoLC is a unique form of medical care, and navigating it requires different tools and information than curative medicine [8]. Staff untrained in EoLC may advocate for therapy to prolong life, misaligned with values of the patients and/or families who would choose to shift goals from prolonging life to comfort [8]. Aggressive care that is misaligned with the patient's and family's values is potentially harmful to patients and/or families, causing a higher burden of symptoms for the patient, stress for the families, and increased moral distress for clinicians. While RTs may not perceive respiratory therapy as a valuable service in EoLC situations [9], they play an important role in recognition and palliation of symptoms [10].

RTs' ability to provide key components of EoLC and self-care depends upon their educational foundation [11]. For RTs EoLC is a combination of experience and instinct, rather than knowledge from formal education and training. No coursework on EoLC, withdrawal of support, or ethical decision-making is mandated for RTs, making them

ill-prepared to deal with emotions associated with EoLC [12–15]. Grandhige et al. [16] found that RTs are not prepared to participate in EoLC discussions, which is consistent with prior findings [1, 17]. In fact, Grandhige et al. [16] found that although the majority of RTs had participated in a terminal extubation at two academic centres in the southeast of the United States, very few spoke directly to patients and/or families at the time of extubation. Covenant Health [18] noted that RTs have varying levels of palliative care expertise depending on how frequently and closely they work with patients who have life-limiting illnesses. Caradine and Lowe [12] concluded RTs consistently lack structured training in EoLC, and more training and discussion was needed for RTs in schools and in the hospital. While the fundamentals of palliative care apply to both adult and pediatrics, having a serious illness is not normal for most children, which can present unique challenges in providing EoLC in this population [19]. Little is known about the EoLC training provided to or needed by pediatric RTs [20].

A survey conducted at our free-standing children's hospital facility prior to the EoLC course found that 40% (25/63) of RTs had received training on EoLC education. Training was equally distributed between school and hospital. RTs rated their knowledge of EoLC as 2.7 out of 5 with 1 = minimal knowledge and 5 = very knowledgeable. RTs with a bachelor's degree or higher education rated themselves as more knowledgeable in EoLC (2.83) than those with associate's degrees (2.07) (Table 1).

On average at our facility 144 inpatient deaths occur annually, with a yearly average of 65 deaths in which RTs are actively involved and a yearly average of 14 compassionate extubations (unpublished data-quality

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management). Prompted by concern for RTs participating in EoLC situations unprepared, we developed a program to introduce practicing RTs to ethical and EoLC issues, the role of respiratory therapy in EoLC, and short- and long-term ways to cope with grief over dying patients. The specific aims of this project are to explore if a new educational course on EoLC care for pediatric RTs increased their perception of knowledge, perceived value of respiratory therapy in EoLC, comfort with EoLC, and knowledge of coping resources. It is hypothesized that providing education on EoLC to RTs will increase their self-perceived knowledge of EoLC, perception of respiratory therapy as a valuable service in EoLC, comfort with providing EoLC, and knowledge of short- and long-term ways to deal with grief.

METHODS

A single-centre Institutional Review Board approved study (#190733) with a descriptive survey was utilized to determine RTs' self-perceived change in knowledge, perception of respiratory therapy as a valuable service in EoLC, comfort with providing EoLC, and knowledge of short- and long-term ways to cope with grief after completion of an EoLC course. The setting was in-person education offered to all pediatric RTs working at the children's hospital on March 18, 2019, and a voluntary online post-educational survey at a free-standing children's hospital associated with an academic program. The survey was accessible online using a QR code immediately after the class with one email reminder including the QR code and link sent 2 weeks later. To minimize frustration and abandonment of the survey, each of the questions in the survey were optional to answer. In addition to the survey questions, we provided an optional comments question to gain more insight surrounding the education.

The primary variables were self-perceived change in knowledge of EoLC, perception of respiratory therapy as a valuable service in EoLC, comfort providing EoLC, and knowledge of short- and long-term ways to cope with their own grief. Other variables included demographic characteristics. Age, years of experience as an RT, sex at birth, and history of education on EoLC were considered.

Internal needs assessment was completed 3 months prior to education and identified knowledge gaps among pediatric RTs related to EoLC. We provided open text space for staff to identify further needs not identified on the assessment survey. We received two comments: "Giving aerosol treatments to the dying patient does not help them, and it feels like a waste of my time" and "When a patient is at end of life there is little I can do to make them more comfortable." Based on the knowledge gap survey and comments, the education course defined compassion, provided clinical training of technical aspects of EoLC, and discussed patient and family privacy, personal/religious/cultural observations, communication, preparing families and patients for end-of-life, signs and symptoms of end-of-life physical changes and breathing pattern changes, palliative care for dyspnea, ethical considerations, body language, death rituals, multidisciplinary care and input, self-care, and internal and external resources available for assistance with grieving. Content was drawn from literature by the author(s) to address identified knowledge gaps [11, 16, 21, 22] and delivered via a 1 h lecture.

Demographics requested were age in years, sex at birth, level of education, and years of RT practice (Table 2). A questionnaire was designed based on a literature search that identified RTs as uncomfortable with their knowledge of EoLC practices, the value of respiratory therapy services in EoLC, caring for EoLC patients, and coping with grief related to care. The 5-point Likert scale questionnaire, designed to answer questions similar to the "attitudes about end-of-life care" by Brown-Saltzman et al. [1] and identify a change in belief of respiratory therapy adding value to EoLC, contained four questions. Responses ranged from 1 = strongly disagree to 5 = strongly agree (Table 3), with a higher score meaning more agreement. Data were analyzed as percentage of total number who answered the item, and we utilized chi squared to compare survey respondent's actual responses to questions with expected answer to assess statistical significance. The open-ended question "How do you feel about this end-of-life care course?" was available for additional feedback to assess qualitatively any benefit of EoLC education.

Data were managed using an online survey format via an electronic link. Participants were assigned a study number and data downloaded into Excel data sheets by participant number. Participants' demographic characteristics were requested but not required, and no name or other identifier was used. Data were stored in a locked computer file that was password protected and only accessible by the primary investigator. Demographic characteristics were analyzed using descriptive statistics and measure of central tendency (median, percent).

RESULTS

One hundred and thirty RTs attended the course and were offered the opportunity to complete an anonymous post-educational self-perception survey. Of the 130 RTs who attended the course and were eligible to participate, 63 completed the questionnaire, resulting in a 49% survey response rate. Each of the questions was voluntary, and not all participants responded to all questions. Historical end-of-life education prior to this course is outlined in Table 1 with RTs who had 15–30 years of experience in the field rating themselves as more knowledgeable of EoLC practices. Results of the participants demographics are presented in Table 2 with more than 42% of the survey participants in the 20–30-year age range, 67% being female, and only 5% having a postgraduate degree. The EoLC education questionnaire results are detailed in Table 3. Overall, 96% (57/60) strongly agreed or agreed that the course increased their knowledge of EoLC, perception of respiratory therapy as a valuable

TABLE 1

Education prior to educational intervention

How many years have you been a respiratory therapist?	Degree level	What was your level of knowledge with end-of-life care prior to the course?*
0–3		2
4–6		2.14
7–10		3
11–15		2.67
16–20		3.4
20–30		4
>30		2.71
	Bachelor's or higher	2.83
	Associate's	2.07

*1 = minimal knowledge, 5 = very knowledgeable.

TABLE 2

Demographics (n = 63)

Age (in years)	n = 59 (4 chose not to disclose)
20–30 (median 24)	n = 25 (42%)
>30–40 (median 32)	n = 15 (26%)
>40–50 (median 45)	n = 10 (17%)
>50–60 (median 53)	n = 9 (15%)
Sex (at birth)	n = 63
Female	n = 42 (67%)
Male	n = 21 (33%)
Level of education	n = 63
Master's	n = 3 (5%)
Bachelor's	n = 29 (46%)
Associate's	n = 31 (49%)
Years of respiratory therapist practice	n = 59 (4 chose not to disclose)
0–5	n = 14 (24%)
>5–10	n = 11 (19%)
>10–15	n = 15 (25%)
>15–20	n = 6 (10%)
>20–30	n = 4 (7%)
>30	n = 9 (15%)

TABLE 3

Respiratory staff perceived benefit of end-of-life education

Answer	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
My overall knowledge of end-of-life care increased (<i>n</i> = 60)	68.3% (41/60)	26.7% (16/60)	0% (0/60)	5% (3/60)	0% (0/60)
Respiratory therapy adds value to care provided to end-of-life patients (<i>n</i> = 62)	67.7% (42/62)	30.7% (19/62)	0% (0/63)	1.6% (1/62)	0% (0/60)
Course made me more comfortable providing end-of-life care (<i>n</i> = 63)	66.7% (42/63)	27% (17/63)	0% (0/63)	6.4% (4/63)	0% (0/60)
Course increased my knowledge of long- and short-term ways to deal with grief (<i>n</i> = 63)	65.1% (41/63)	31.7% (20/63)	0% (0/63)	3.2% (2/63)	0% (0/63)
Overall	67%	29%	0%	4%	0%

Note: Each survey question was optional; number of respondents varies.

service in EoLC, comfort with providing EoLC, and knowledge of short- and long-term coping skills. Only 4% felt that this course had little benefit overall but still perceived respiratory therapy as adding value to EoLC and found the course increased knowledge of short- and long-term ways to cope with grief. There were no statistical differences between participants regarding age, level of education, or years of RT practice.

There were three free text comments in response to the open-ended question “How do you feel about this end-of-life care course?”: “Offering classes on end of life seems to be greatly beneficial,” “Where was this class 30 years ago?,” and “I certainly did not get this in school, and I now realize how important of a role we play in end-of-life care.” Due to the low volume of answers, we were unable to complete thematic analysis.

DISCUSSION

The need for EoLC education for RTs is supported in literature [17, 23]. As more RTs are successfully being incorporated into new models of interdisciplinary palliative [14], the need for more EoLC is growing for both inpatient and outpatient RTs. Our study demonstrates that providing education in EoLC can improve pediatric RTs' comfort with and perception of knowledge in EoLC and coping with grief, as well as their understanding of the value of the RT role in EoLC. Without training and the tools that help with deal with end-of-life care, RTs are likely to be at risk for burnout, depression, and moral distress [23]. Healthcare providers struggle with providing palliative care and often feel they have failed the patient or feel helpless in EoLC situations. Research has shown that with proper education and programs, there is a change in short-term RT comfort and role perception in EoLC [1]. Nursing literature demonstrates that a lack of confidence or knowledge of EoLC practices is a contributor to moral distress [24–26], however, moral distress can be limited by improving knowledge and comfort in providing EoLC [27]. The impact of interventions like those we described would likely have similar impact, and the correlation to moral distress bears further study.

RTs are there when end of life is imminent, but most find it difficult to remove life support because they were trained to keep people alive. End-of-life education is able to empower clinicians from all specialties to use their knowledge to palliate end-of-life symptoms, making the patient more comfortable [10]. Healthcare professionals who understand the process of dying can provide clear communication and simple explanations that can ease the anxiety and uncertainty around death, instead of advocating for therapy that may increase life [28]. Without proper education, RTs may be unaware of the benefit of respiratory therapy at alleviating pain and providing comfort, leaving them less likely to advocate for appropriate symptom management for their patients. Without an understanding of the dying process and associated physical changes, clinicians are ill-prepared to provide EoLC [29], which could result in potential distress for patients, families [30], and the RTs themselves [23]. Ongoing assessment of staff and development of programs to support RTs that include specialized education, self-care resources, and staff bereavement programs may decrease professional stressors that lead to compassion fatigue [31]. The educational intervention we described represents one such program that may improve compassion fatigue, and this possible correlation bears further study. Proper

training can help RTs cope with their role in palliative care and add special meaning to the process [1, 10].

Limitations to the study deserve mention. This was a self-rated perception survey, and we were not able to assess families' perception or actual impact on care as noted by other members of the team. This is in part limited by the fact we chose not to survey parents of a recently bereaved family. We also did not directly assess knowledge in EoLC or coping with grief and instead used RT perception of change in these areas. However improved self-rated knowledge may indicate improved confidence, when facing these clinical situations, mitigating distress. Other limitations include that perception was assessed shortly after the intervention, but how long the effect lasted is unknown/not assessed. Similarly, self-perception around coping with grief is used as a proxy for coping, as opposed to assessing coping using a standard scale. This survey was subjective and may have bias in self-reporting; however, the use of a subjective survey was intended to measure the respondent's feelings and perceptions. There was a small sample size and low response rate (49%) that can be associated with an inflated effect size estimation and low statistical power, and there is potential for non-response bias. Attempts were made to reduce non-response bias by limiting the number of survey questions and not making each survey question required. This survey also relied on volunteers, and so there may be some volunteer bias, but it is difficult to estimate the impact of this bias, although volunteers tend to be more educated [32]. To eliminate some of the volunteer bias, the questions were kept short and clear with precise language, and the answers were simple and straightforward.

CONCLUSIONS

In this study education on EoLC practices increased pediatric RTs' perception of knowledge, perceived value of respiratory therapy, comfort in EoLC, and knowledge of short- and long-term means of coping with grief. The success of this intervention on a small group suggests that EoLC education for RTs may have an impact on coping, similar to impacts on nursing. The levels of knowledge prior to this intervention noted in Table 1 indicate a strong need for EoLC education for RTs, especially those with 0–20 years of experience and greater than 30 years of experience. Very little research has been conducted regarding RTs' ability to cope with death and dying after repetitive removal of life support, their degree of compassion fatigue, or what education should be included in EoLC for RTs. More research including a larger group of RTs, improving response rates of participants, and streamlining the education provided to meet the needs of the participants is needed. Directions for further study include examining persistence over time of perception of improved knowledge and comfort and directly assessing connection between these educational interventions and participants' compassion fatigue.

DISCLOSURES

Contributors

DL, literature search, data collection, study design, analysis of data, manuscript preparation, review of manuscript. TP, literature search, review of manuscript. AD, review of manuscript.

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Competing interests

All authors declare no conflict of interest.

Ethical approval

This study was approved by a single-centre Institutional Review Board (#190733). Study was performed at Rady Children's Hospital - San Diego, 3020 Children's Way, San Diego, CA 92123, United States.

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