Changes in Medical Care at a Pediatric Oncology Referral Center after Placement of a Do-Not-Resuscitate Order

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Abstract

Objective: Parents may fear that a do-not-resuscitate (DNR) order will result in reduction of the level, quality, and priority of their child's medical care. We therefore assessed medical care that was continued, added, and discontinued after a DNR order was placed in the medical record.

Patients/methods: Retrospective review of the charts of 200 pediatric oncology patients at St. Jude Children's Research Hospital who died between July 1, 2001 and February 28, 2005, were younger than 22 years old at death, and had a documented DNR order. Medical interventions that were added (between the DNR order and death), continued (not discontinued between 24 hours before and 72 hours after DNR), and discontinued (within 72 hours after DNR) were identified and compared by using binomial proportions.

Results: With the exception of chemotherapy, the studied medical interventions that patients were receiving at the time of the DNR order were continued in 66.7% to 99.3% of cases. Chemotherapy was continued in 33.3%. The most frequently added interventions were oxygen, steroids, and pain medicine. The most frequently discontinued interventions were laboratory draws, chemotherapy, antibiotics, and parenteral nutrition.

Conclusions: In this cohort of pediatric oncology patients, the medical interventions being received were continued with a high frequency after placement of a DNR order. Chemotherapy was continued only in a minority of patients, possibly signifying a shift in goals. These findings may help to reassure families that a DNR order need not result in a change in any of their child's medical therapies which appropriately advance the defined goals of care.

Introduction

A DO-NOT-RESUSCITATE (DNR) order¹ is intended only to protect the patient and clinician from resuscitative attempts that are not warranted or are not desired by the patient. Early guidelines urge that "nothing in the entire [DNR] procedure should indicate to the patient and family any intention to diminish the appropriate medical and nursing attention to be received by the patient."¹ However, early studies of attending physicians, resident physicians, nurses, and families identified differences in the care received by clinically similar patients who did and did not have a DNR order.^{2,3} In adults, DNR orders have been linked to fewer medical interventions, a lower likelihood of physiologic monitoring, and

less use of aggressive life-sustaining interventions (e.g., intensive care unit [ICU] admission, central line placement).⁴⁻⁶ These findings suggest that a DNR order is one of a series of measures limiting medical interventions in the context of severe or terminal illness.⁴

In pediatrics, decision making about end-of-life care (EOLC) is recognized as an important research priority,⁷ but there are no available data about the impact of DNR orders on nonresuscitative care. Although no discussion of advance directives and DNR orders is required by pediatric health care oversight agencies, there has been a movement over the past two decades toward earlier discussion of end-of-life issues and the integration of palliative care principles into the continuum of care of children with complex chronic conditions.^{8,9}

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Parents find end-of-life decisions (including DNR) to be among the most difficult they must make for their child,¹⁰ and clinicians feel inadequately prepared to help with this process.¹¹ The uncertainties that beset parents who must make EOLC decisions may be exacerbated by concern about the medical care their child will receive after placement of a DNR order in the medical record.

The purpose of this study was to better understand the frequency and type of alterations in common medical interventions after placement of a DNR order in children with cancer at the end of life. We reviewed specific types of medical care provided before and after the placement of a DNR order in this cohort of children at our institution.

Methods

The institutional medical records of patients treated at St. Jude Children's Research Hospital who died during a 44-month period (July 1, 2001 to February 28, 2005) were reviewed after approval by the hospital's Institutional Review Board. Two hundred patients met the inclusion criteria for this study (oncologic diagnosis, age less than 22 years, and a DNR order on the chart at the time of death). After conducting an extensive review of the literature and requesting recommendations from a panel of palliative and end-of-life care experts, we created a data collection form listing common interventions received by children with cancer at the end of life. All information was collected on this data form. Each patient's medical record was examined to identify treatments (defined in Table 1) that were added (between the DNR order and death), continued (present 24 hours before and not discontinued 72 hours after DNR), and discontinued (within 72 hours after the DNR). For the purpose of this study,

we defined a DNR order as any "do not resuscitate" order on the chart, regardless of specific exemptions in the order. An "other" category was added to the data extraction form to allow researchers to record medical interventions that were not among those prospectively defined. This category was completed at the discretion of the chart reviewer and interventions were not further analyzed. We specified a 72-hour period after the DNR order for discontinuation of a treatment because this time frame maximized the probability that the discontinuation was related to the DNR order while including the fewest discontinuation orders entered for other reasons (e.g., completion of an antibiotic course).

Each patient's full medical record was reviewed a second time by a different member of the study team to verify the data. The study team was trained in an ongoing manner (initially and every 3 months) regarding use of the data extraction form and variable dictionary. Discrepancies (e.g., in interpretation of chart notes) were resolved by study team discussion or, when necessary, a more focused review of the medical record. Data were then transferred to an Excel spreadsheet, and the accuracy of data entry was verified for every third case by a different study team member. A level of accuracy greater than 95% (more than 95 data fields verified as correct per 100 comparisons) was maintained.

Statistical analysis

We calculated the percentage of the total cohort in which specific interventions were added, continued and discontinued. We then calculated the percentage (plus exact 95% confidence interval) of patients for whom specific interventions being provided at the time of DNR were continued $[N \text{ continued} / (N \text{ continued} + N \text{ discontinued})] \times 100$ for more than 72 hours following the placement of the DNR order in the chart.

Results

The mean time from placement of a DNR order to death was 34 days (SD, 62.8 days). Table 2 summarizes the characteristics of the 200 patients who had a documented DNR order at the time of death. Table 3 lists medical interventions that were added, continued, or discontinued after a DNR order was recorded. With the exception of chemotherapy, medical interventions that patients were receiving at the time of the DNR order were continued in 66.7% to 99.3% of cases. Chemotherapy was continued in 33.3%. The three most commonly added interventions were oxygen, steroids, and pain medicine. The most commonly discontinued interventions were laboratory draws, chemotherapy, antibiotics, and parenteral nutrition.

Discussion

As stated above, DNR orders in adults have been linked to fewer medical interventions, a lower likelihood of physiologic monitoring, and less use of aggressive life-sustaining interventions (e.g., ICU admission, central line placement).^{4,5,7} In contrast, this descriptive study suggests that in children with cancer, most aspects of treatment are not altered when a DNR order is placed on the chart. It is important to note, however, that in our study chemotherapy was continued less frequently than other interventions during the 72 hours after the DNR order. Furthermore, the three most commonly added inter-

TABLE 1. DEFINITIONS OF THE INTERVENTIONS EXAMINED

Antibiotic—bacterial antimicrobial agent (<i>Pneumocystis</i> pneumonia prophylaxis not included)
Anticonvulsant—antiepileptic drug
Antifungal—fungal antimicrobial agent
Antiviral—viral antimicrobial agent
Blood products—PRBCs, platelets, FFP, other blood bank products
Chemotherapy—medical intervention directed toward managing the cancer
Hemodialysis/CVVH—intermittent dialysis or continuous veno-venous hemofiltration
IVF—intravenous fluid provided for any reason
Lab draws—serum chemistries, CBC, other routine laboratory tests, etc.
Invasive mechanical ventilation—via endotracheal tube or tracheostomy
Oxygen—supplemental oxygen via nasal cannula or other mechanism
Pain medications—opioids, acetaminophen, NSAIDs, etc.
Parenteral nutrition—TPN/intravenous nutrition
Radiation therapy—any course of planned radiation therapy—palliative or otherwise
Steroids—corticosteroids including dexamethasone, prednisone
Surgery—any surgery
Vasopressor—inotrope

TPN, total parenteral nutrition; PRBCs, packed red blood cells; FFP, fresh frozen plasma; CBC, complete blood count.

TABLE 2. CHARACTERISTICS OF THE STUDY GROUP (N=200)

Characteristic	n (%)
Gender	
Female	76 (38.0)
Male	124 (62.0)
Race ^a	
White	130 (65.0)
Black	48 (24.0)
Other	22 (11.0)
Diagnosis	
Leukemia	68 (34.0)
CNS tumor	69 (34.5)
Other solid tumor	63 (31.5)
Allogeneic HSCT	41 (20.5)
Place of death	
Hometown hospital	18 (9.0)
Home	92 (46.0)
St. Jude Inpatient Care	74 (37.0)
St. Jude Domiciliary Care	6 (3.0)
Unknown	8 (4.0)
Other	2 (1.0)
Religion ^b	
Protestant	135 (67.5)
Catholic	45 (22.5)
Other	20 (10.0)

^aRace was self-reported. "Other" indicates any race other than white and black.

^bReligion was self-reported. "Other" indicates any religion other than Protestant and Catholic Christian.

HSCT, hematopoietic stem cell transplantation; CNS, central nervous system.

ventions were oxygen, steroids, and pain medicine, while the most commonly discontinued interventions were laboratory draws, chemotherapy, antibiotics, and parenteral nutrition. These findings likely reflect shifting goals of care in many patients and families. Earlier studies showed that parents of children with progressive cancer may continue to desire all interventions seen as beneficial to or in the best interest of their child, whether for comfort or for prolongation of life.¹² Our findings could help to reassure families that a DNR order need not result in a change in their child's medical care but is instead a tool to ensure that the patient's and family's wishes about resuscitation at the end of life are honored.

Interestingly, in this study, children with advanced cancer were receiving a complex medical regimen at the time of the DNR order. Many patients were undergoing 10 or more medical interventions, and very few were added after the DNR order. The fact that mechanical ventilation was not added to the treatment of any patient after a DNR order appears to demonstrate the growing recognition and respect for nonresuscitative end-of-life goals in this patient population. Comfort measures were added more frequently than they were discontinued after a DNR order, likely reflecting a shift in the goals of care. Although infrequent, the addition of interventions such as surgery, continuous veno-venous hemofiltration (CVVH)/hemodialysis, and vasopressors shows that physicians continue to support the use of life-prolonging interventions desired by parents in the presence of incurable illness. This finding further suggests that while a DNR order may signal a shift in care goals, it does not preclude the use of life-prolonging measures.

TABLE 3. DISTRIBUTION OF INTERVENTIONS AFTER DO-NOT-RESUSCITATE ORDER (N=200)

Intervention	Added n (% total)	Continued n (% total)	Discontinued n (% total)	Not applicable ^a n (% total)	% Continued ^b (exact 95% CI)
Antibiotics	8 (4.0)	96 (48.0)	18 (9.0)	78 (39.0)	84.2 (76.2, 90.4)
Anticonvulsants	4 (2.0)	37 (18.0)	2 (1.0)	157 (78.5)	94.9 (82.7, 99.4)
Antifungals	7 (3.5)	52 (26.0)	9 (4.5)	132 (66.0)	85.3 (73.8, 93.0)
Antivirals	2 (1.0)	26 (13.0)	5 (2.5)	167 (83.5)	83.9 (66.3, 94.6)
Blood products	3 (1.5)	74 (37.0)	3 (1.5)	120 (60.0)	96.1 (89.0, 99.2)
Chemotherapy	7 (3.5)	13 (6.5)	26 (13.0)	154 (77.0)	33.3 (19.1, 50.2)
Hemodialysis/CVVH	2 (1.0)	12 (6.0)	3 (1.5)	183 (91.5)	80.0 (51.9, 95.7)
IV fluids	10 (5.0)	79 (39.5)	7 (3.5)	104 (52.0)	91.9 (84.0, 96.7)
Lab draws	0 (0.0)	89 (44.5)	27 (13.5)	84 (42.0)	76.7 (68.0, 84.1)
Mechanical ventilation	0 (0.0)	33 (16.5)	9 (4.5)	158 (79.0)	78.6 (63.2, 89.7)
Oxygen	26 (13.0)	59 (29.5)	8 (4.0)	107 (53.5)	88.1 (77.8, 94.7)
Pain medications	13 (6.5)	145 (72.5)	1 (0.5)	41 (20.5)	99.3 (96.2, 100.0)
Parenteral nutrition	9 (4.5)	54 (27.0)	14 (7.0)	123 (61.5)	79.4 (67.9, 88.3)
Radiation therapy	4 (2.0)	6 (3.0)	3 (1.5)	187 (93.5)	66.7 (29.9, 92.5)
Steroids	15 (7.5)	80 (40.0)	5 (2.5)	100 (50.0)	94.1 (86.8, 98.1)
Surgery	5 (2.5)	3 (1.5)	1 (0.5)	191 (95.5)	75.0 (19.4, 99.4)
Vasopressors	7 (3.5)	24 (12.0)	9 (4.5)	160 (80.0)	72.7 (54.5, 86.7)
Other ^c	27 (13.5)	75 (37.5)	5 (2.5)	93 (46.5)	93.8 (86.0, 97.9)

^aTotal N - (N Added + N Continued + N Discontinued), representing the number of patients who did not receive the specified intervention.

^bN continued/(N Continued + N Discontinued) × 100.

^cThis category included medical interventions not prospectively defined but entered on the data extraction form at the discretion of the chart reviewer (e.g., antipsychotics).

CI, confidence interval; CVVH, continuous veno-venous hemofiltration; IV, intravenous.

This study had important limitations. First, the study was conducted at a single tertiary pediatric oncology referral center. Second, it was retrospective and therefore did not allow the opportunity to directly query clinicians and families about the rationale for the addition, continuation, or discontinuation of interventions. In this design, we were limited to examining what was documented in the medical record. Interventions not specified on the data extraction form and interventions added or discontinued at a location other than St. Jude may have been missed. Further, we included in the "discontinued" category any intervention that was stopped for any reason during the 72 hours after the DNR order. This method maximized the likelihood that the discontinuation was related to the DNR order; however, given that the mean time from placement of a DNR order to death was 34 days, a number of therapies discontinued due to the DNR order beyond that time point may not have been captured. It was also difficult to determine the direct relation of a DNR order to the addition, continuation, or discontinuation of an intervention in the absence of a control group. As we previously reported, only 31 patients who died during the same period had no DNR order.¹³ This proportion (31/231, 13.4%) is much smaller than that in adult patients with cancer, making direct comparisons between these cohorts uninformative.

At the time of this study, the DNR order forms used at St. Jude Children's Research Hospital were procedure-related. In January 2007, we converted to a DNR order form (Physician Orders for Scope of Treatment; POST) that addresses both procedures and goals and is valid throughout the state in both inpatient and outpatient settings. This change warrants further study of the timing of the DNR order's introduction and the impact of the POST on the treatment of pediatric patients with incurable illness.

Conclusion

In this cohort of pediatric oncology patients, ongoing medical interventions (with the exception of chemotherapy) were continued with a high frequency after the placement of a DNR order. These findings may help to reassure families that a DNR order need not result in the withdrawal of otherwise clinically indicated medical care.

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Author Disclosure Statement

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