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Interdisciplinary Communication: Documentation of Advance Care Planning and End-of-Life Care in Adolescents and Young Adults with Cancer

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INTRODUCTION

Despite the importance of initiating advance care planning (ACP) prior to end-of-life (EOL), documentation of this practice in the electronic health record (EHR) has not been standardized and therefore evidence that it has occurred is difficult to find, especially in the pediatric population.^{1–4} For example, one retrospective case review of 20 deaths of children with life-threatening or life-limiting conditions showed that 25% had no documented discussion about the approach to EOL, 25% of cases lacked any evidence of ACP, and almost half of families were not offered an option about preferred place of care or place of death.⁵ In addition, for parents of chronically ill children, experience with, and understanding about, advance directives are very limited.^{6–8} While ACP conversations are very personal and historically have been contained within the physician-patient relationship, the expansion of the number of care providers and care teams requires that the EHR be an integral tool for communicating about ACP and documentation of EOL preferences across care settings, especially for nurses who provide the majority of direct care.^{9,10} In addition, because there are differences between physician and nurse perspectives on 1) timing and content of EOL discussions, 2) use of inappropriate interventions, 3) lack of informed consent, and 4) the degree of patient and family suffering have been reported in the

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literature,^{11–13} transparent access to information is critical to the inclusion of all provider viewpoints in these difficult situations.

Ideally, on the top of the initial summary page of the EHR for all disciplines should be a link to the most recent note or home page about goals of care. While there is evidence of improved documentation of EOL communication with the growth of palliative care programs,^{14–15} these changes have yet to become standard of care. Furthermore, in addition to being a communication tool for clinical care across disciplines and care locations, EHR documentation of pediatric ACP conversations and treatment preferences could also be a key factor in examining the influence of ACP on outcomes, as it contains large amounts of information such as detailed demographics, historical material with time markers, and comorbidities.

For the present study, a review of EHR documentation was conducted on a sub-sample of adolescents and young adults (AYAs) with cancer who had participated in a previously reported ACP prospective randomized clinical trial¹⁶ who had subsequently died. Goals of this secondary analysis were to assess the EHR of a large tertiary care pediatric hospital for inclusion of discussions about goals of care, and details about preferences and the actual care delivered at EOL.

METHODS

The original study participants were 30 AYAs (ages 14 to 21) and their designated surrogates. Eligibility criteria, methods and results have been previously published.¹⁶ Eligibility was not based on prognosis and patients were either in active medical treatment or post-treatment with curative intent. After eligibility criteria were met, dyads consisting of the AYA and a legal guardian (if < 18 years of age) or designated family member (if over 21) were computer randomized to a study arm. The intervention group experienced Family CEntered (FACE) ACP discussions in 3 weekly 60-minute sessions, while the control group received information about ACP in brochure form but no facilitated conversations.¹⁶ All participants completed an ACP instrument – a “Statement of Treatment Preferences,”¹⁷ and the participants in the intervention group, and one patient in the control group (outside of the original study) had completed an advance directive (“Five Wishes”¹⁸). The advance directive was included in the EHR as part of the original study protocol. Results indicated more congruence in treatment preferences between the members of the treatment dyads compared to the control dyads, who were also more like to agree about treatment limitations, and better information retention about EOL decision-making for the intervention AYAs.¹⁶

Of the 17 intervention and 13 control AYAs in the original study, 9 had died at the time of the completion of the chart review for the secondary analysis (approximately 3 years after the conclusion of the original study). One patient died at another hospital and access to the EHR was not possible, so this patient was excluded in the current analysis. Five of the remaining patients had been in the control group, and 3 in the intervention group.

The inpatient or outpatient encounters were initially reviewed by an oncology fellow (2nd author) for 6 of the 8 patients in a spreadsheet format after receiving IRB approval. The first

author, with extensive experience in chart review as site coordinator for a large-scale critical care clinical database, then abstracted the final list of variables of interest and detailed them in a timeline summary by days after diagnosis (Day 0) for all 8 patients. Hospital discharge summaries, social work notes, chaplain notes, palliative care team notes, family meeting notes, event notes, and clinic visit records and letters were examined. These timeline summaries were then matched to the initial spreadsheet and any discrepancies rectified. The additional 2 patient charts were then summarized by timeline by the first author.

Documentation about disease trajectory (time from diagnosis to death), invasive interventions, emergency department visits, and hospitalizations (ICU days and acute care floor days) was reviewed for the last 30 days of life to capture EOL care.¹⁹ In addition, documentation that a discussion around goals of care had been conducted and their location in the EHR were identified. Goals of care discussions were defined as those concerning illness understanding, comfort versus curative treatment options, or EOL preferences.²⁰ Finally, the following variables were examined across disease trajectory: referral to palliative care, referral to hospice, presence of an advance directive, surrogate decision maker identified if over age 18, limitations on care, and location of death.

RESULTS

The AYAs in this secondary analysis ranged in age from 14 to 19 years at diagnosis. Four patients had solid tumors C1, C4, I1, and I3), 1 patient had a brain tumor (C5), and 3 had leukemia (C2, C3, and I2). Table 1 describes hospital utilization, invasive interventions for the last 30 days of life, additional characteristics of EOL care, and responses to the ACP instrument and advance directive from the original study. All 8 patients were eventually followed by the hospital palliative care team. Intervention AYAs received earlier referrals to palliative care services (241–447 days) compared to controls (2–84 days) before death. Three of the 8 had documented referrals to hospice in the chart, and there was evidence that 4 had participated in home hospice at some point in their disease trajectory. For the 4 participants who died above the age of 18 (2 intervention and 2 control), a surrogate decision maker had been identified. All 8 had evidence of limitations placed on their care (i.e., life-saving or life-extending interventions were not to be utilized or were withdrawn) in the chart, with variability in the length of time to death between 1.5 hours up to 2 months.

Table 2 provides a narrative summary of the last 30 days of life for each patient with respect to EOL care. Two participants died at home, 2 in an ICU, and 4 in an acute care floor bed at a pediatric hospital, and the chart review for these 8 patients suggested multiple instances of poor quality in the dying and death process.^{1,22,22} For example, for one patient, despite participation in the intervention group, care provided by the hospital palliative care team, and a Do-Not-Intubate order in place during the EOL period, parental disagreement led to an invasive interventional procedure that resulted in a cardiopulmonary collapse with emergent intubation and admission to an intensive care unit where the patient died 3 days later. For another patient who had been in and out of hospice care, a patient went to an outside hospital emergency room for severe respiratory distress and was intubated. Family members were surprised by the rapid worsening of disease progression and how choices were presented about the intubation in the emergency room. The patient was transferred to the

pediatric hospital, and extubated with an “allow natural death” order in place within a few days.

The clinical trial also anecdotally revealed the degree to which documentation of EOL preferences can be exceptionally useful to care at EOL. Physicians for 2 control adolescents contacted the principal investigator (last author) when the AYAs’ condition deteriorated, requesting a copy of the patients’ self-reported treatment preferences, which had been completed without a facilitated conversation with the family. This information was released to the treating physician. In each instance, the physician and family reviewed the AYA’s self-report and made decisions in light of the AYAs’ EOL treatment preferences. One adolescent had already had a bone marrow transplant and indicated a wish not to pursue further treatments, if she were to relapse again. The physician and mother together decided to honor her preferences and did no further intervention following a medical crisis triggered by a new cancer drug. The release of this information to the two treating physicians of control participants potentially contaminated the study results, but was in keeping with the ethical principle of having the welfare of the research participant as the primary goal.

In another instance, again with a control patient, a conflict emerged between the chosen surrogate decision-maker of a 20 year old patient, who chose a non-biological family member, rather than the young adults’ biological mother. The patient’s mother strongly felt her role was to have everything done to prolong her child’s life, while the surrogate represented the wish of the young adult for limits of care under the current circumstances. An ethics consultation was requested and a family meeting held with all involved, which led to a resolution in accordance with the young adult’s wishes.

DISCUSSION

Examination of the last days of life for these patients underscores the complexity of decision-making at EOL and the current difficulty in determining from the EHR if the care desired is the care received, particularly for non-physician caregivers.²³ ACP and EOL decision making in the pediatric population may contrast significantly from the adult population, with many parents indicating that there really aren’t decisions to be made – all treatment must be attempted for a child if presented as an option for care.²⁴ This can be seen in the preferences and wishes expressed by the patients in this review. However, a survey of 96 respondents, which included both health care providers and families, found a minority of clinicians, but 100% of parents, thought all pediatric inpatients warranted Medical Orders for Life-Sustaining Treatment discussions.²⁵ Poor quality of dying - dying in the setting of continued invasive and often futile interventions after a long illness, lack of documentation of the patient’s wishes, conflict concerning goals of care between family members, and unclear understanding of disease trajectory and prognosis - is undesirable for patients of any age.^{17,26–29}

The majority of the documentation about goals of care conversations came from outpatient clinic letters or palliative care notes and letters. This severely limits the accessibility of information available about ACP, especially for hospitalized patients who have extensive needs for nursing care that is best provided when these important additional perspectives and

information about the patient and family are efficiently tracked across location. The EHR should be modified to provide detailed individualized care planning and coordination grounded in documented patient- and family-preferences across both the outpatient and inpatient settings.^{30,31} Ideally, the EHR format clarifies not just ACP goals of care but also documents health system steps and processes that enable and foster implementation of ACP tasks such as communication with home nursing agencies, access to medical supplies in the home, and potential hospice services available in any given geographic region. Simple EHR information like ICU or length of stay does not capture the kind of quality metrics that are needed to provide exceptional care at the bedside and assess the impact of ACP on EOL.¹⁹

“Care and Communication Bundles,” modeled after other evidence-based, proactive care protocols, have been successfully designed and implemented in adult settings to standardize multidisciplinary planning, documentation, and discussions about goals of care.^{32,33} These protocols instantiate the key features of an expanded inter-professional team approach: “The team [which includes the patient and family] must provide integrated and cohesive care and share power among its members. The team members must be able to exercise their partnership and share their knowledge regularly and without interruptions, communicating information systematically throughout the therapeutic process and using well-designed information and communication technologies.” (p. 562).³⁴

In conclusion, this study examined EOL care for deceased AYAs who had participated in an ACP intervention. With the increasing appreciation for engaging pediatric and AYA patients and their families in ACP in meaningful ways, the health system will benefit from documenting goals of care in a central, accessible, and standard format in the EHR. Strategies to bolster ACP and documentation of EOL quality metrics in the EHR should promote better integrated and interdisciplinary palliative care.^{35,36}

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Table 1:

EOL care and treatment preferences by case

	Cases (C=Control group I=Intervention group)							
Patient	C1	C2	C3	C4	C5	I1	I2	I3
Diagnosis to Death (days)	846	316	465	1154	1976	556	1329	1347
Palliative Care referral (days before death)	11	11	2	184	30	241	370	447
Hospice referral (days before death)	10	None	None	113	None	4	None	None
Location of death preference	Home	Unk	Unk	Unk	Floor	Home	Unk	Unk
Location of death	Home	Floor	ICU	Floor	Floor	Home	Floor	ICU
Age at death (years)	15.9	15.2	17.5	20.1	23.9	19.4	17.2	20.8
Surrogates Identified	NA	NA	NA	Y	Y	Y	NA	Y
Advance Directive in Chart	N	N	N	N	Y	Y	Y	Y
Limits of Care (days before death)	9	11	0	1	331	5	3	Unk
Diagnosis to last 30 days of life/Last 30 days of life								
# Emergency Department visits	2/1	1/NA	0/NA	9/1	3/NA	2/1	10/NA	4/2
# inpatient Intensive Care Unit days	0/0	86/19	0/4	2/2	3/4	6/0	55/5	0/3
# inpatient floor days	86/8	28/11	186/26	65/6	14/26	111/1	189/25	66/0
Intubation	N/N	Y/Y	N/Y	N/Y	N/N	N/N	x2/N	N/Y
Cardiopulmonary resuscitation	N/N	N/N	N/Y	N/N	N/N	N/N	N/N	N/Y
Dialysis	N/N	Y/Y	N/Y	N/N	N/N	N/N	Y/N	N/N
Inotropes	N/N	N/N	N/Y	N/N	N/N	Y/N	Y/N	N/N
Total Parental Nutrition	N/N	Y/Y	N/Y	Y/N	N/N	N/N	Y/Y	N/N
Ventriculo-peritoneal shunt	N/N	N/N	N/N	N/N	Y/Y	N/N	N/N	N/N
Tracheostomy	N/N	Y/Y	N/N	N/N	N/N	N/N	N/N	N/N
Statement of Treatment Preferences								
1 – long hospitalization, low chance	LS	LS	LS	DK	missing	LS	LS	LS
2 – long hospitalization, no chance	No LS	LS	DK	LS	missing	LS	LS	No LS
3 – can't walk/talk, need 24hr care	No LS	LS	LS	LS	missing	LS	DK	LS
4 – neuro-devastation, need 24h care	LS	LS	LS	DK	missing	LS	DK	LS
5 Wishes								
“if I am close to death”	-	-	-	-	Doc	Doc	LS	Doc
“if I will experience brain damage”	-	-	-	-	Doc	LS	Doc	Doc
“if I will be in a permanent coma”	-	-	-	-	Doc	LS	Doc	No LS

Abbreviations: NA=Not Applicable, N=No, Y=Yes, Unk=Unknown, LS=wants life-saving treatment, No LS=does not want life-saving treatment, Doc=only if doctor thinks it would help, DK=don't know

Table 2.

Narrative summary of end-of-life care by case

Case (C=control, I=Intervention)	Description of EOL
C1	The tumor at the original site and metastases were growing and the patient was ineligible for any experimental trials due to disease progression. The patient was experiencing pain, urinary retention problems, and increasing respiratory issues. A palliative consult was held where the patient and family focused on symptom management, not psychological issues or goals of care. An emergency room visit for difficulty breathing occurred and the patient was admitted to hospital for 8 days. The family agreed to care restrictions on the 2nd day of this hospitalization (no intubation, intensive care transfer, or cardiopulmonary resuscitation), and the use oxygen and fluids for comfort only. The patient was anxious about going home, and the decision about when was left up to the patient by the family. "Do not resuscitate" orders were completed prior to discharge, and death occurred 4 days after the return home.
C2	A bone marrow transplant was done on this patient with psychological support services post-transplant while inpatient as the patient's condition was poor. Two months later, the patient was transferred from the acute care floor to the intensive care unit after complications developed. Over the next 2 months, the patient needed to be intubated and placed on a ventilator and then had a tracheostomy. The patient then experienced an event leading to neurological devastation. Five weeks later, a decision was made to allow a natural death due to disease progression and brain damage. The patient was transferred back to the acute care floor. Two weeks later the family decided to reverse the limitations of care order and then 1 week later reversed their decision again. The patient died in the hospital 1 week later.
C3	The patient was admitted to the hospital for fungal pneumonia. The chances of cure were low, and the doctor had seen documents from the original ACP study which stated that the patient and family wanted aggressive treatment in all situations. Psychological counseling was ongoing. The patient received chemotherapy for a relapse, experienced significant adverse effects, and was admitted to the intensive care unit. Documentation in the EHR indicated that a palliative care consult had been initiated but there were no notes from the palliative care team. Due to the adverse effects, chemotherapy was stopped. The patient became septic and reported pain levels of 9 out of 10. The patient remained with no limitations to care, and was intubated and treated with dialysis and life-sustaining medications. These interventions failed and the patient's heart stopped and shocks to restore heart rhythm were delivered 11 times. After this event, the family agreed to a "Do not resuscitate" order and the patient died after going into cardiac arrest again.
C4	The patient and family were never willing to fill out an advanced directive but the medical team did get the patient's verbal designation of a surrogate decision maker in case the patient became unable to make decisions. The patient was on home hospice and off curative chemotherapy due to disease progression and had significant nausea, vomiting, and diarrhea for many months. The patient had plans to go back to school and began an experimental trial. The patient was admitted for 1 day for breathing difficulties and then went home for 2 days before returning to the emergency room with impending respiratory failure. The patient chose to be intubated and placed on mechanical ventilation in the emergency room after saying loving words to family, and was then transferred to the intensive care unit. The patient's mother was upset about the rapid deterioration and had to be convinced it was due to disease progression. She was also angry with how choices were presented at the emergency room. After one day in the intensive care unit, the mother chose to have to take the patient off of the ventilator and remove the intubation tube. This was done after the patient was transferred to the acute care floor and death occurred soon after.
C5	The patient was able to go on their honeymoon although experiencing mental status changes. The patient had been on home hospice at times although it was unclear whether it was always maintained across hospital admissions. Due to cognitive deterioration, a brain shunt was inserted but did not change the consequences of tumor progression. A member of the patient's family had concerns that the 5 Wishes advance directive that the patient had filled out previously was not consistent with the patient's true wishes. The document was reviewed by the care team. This family member was not the patient's designated surrogate decision maker. The patient's wishes were to allow a natural death and they preferred to die in the hospital. These wishes were honored and the patient died without life-sustaining interventions in the hospital.
I6	The patient was enrolled in an experimental trial but chemotherapy doses were being held due to drug toxicity and adverse side effects. The patient and family chose to stop all treatments and utilize comfort care measures only. Hospice had been discussed many times as the patient's disease progressed, but the family refused although they desired for death to occur in the home. The patient was admitted through the emergency room for breathing difficulties and there was evidence that metastases in the lungs had grown worse. A "Do not resuscitate" order was put into place, and the patient went home. The patient died 4 days later with home hospice services.
I7	The patient was post bone marrow transplant and on dialysis. The patient became septic and went into shock and was transferred from the acute care floor to the intensive care unit. In spite of multiple additional medical interventions, the patient went into multi-system organ failure. After some recovery, the patient was transferred back to the acute care floor but then required a return to the intensive care unit. Up until this time, the family had requested that all interventions to sustain life be maintained, however during this second transfer, they decided on a "Do not intubate" order. The patient died 3 days later after a return to the acute care floor.

Case (C=control, I=Intervention)	Description of EOL
18	<p>The patient had been enjoying a very good quality of life as their tumor progressed, maintaining a stable weight, using marijuana for symptom control, off chemotherapy, and seeing both the palliative care team and psychology. The patient had a "Do not intubate" order in place. The patient missed clinic appointments due to a lapse in insurance, and then developed a worsening cough, audible breath sounds, and increased fatigue. The patient required a wheel chair, experienced additional sleepiness from the pain medications but also had difficulty sleeping due to the cough, which sometimes led to pieces of tumor being expelled from the lungs. A test was performed at an outside hospital to look at the lungs and during the procedure the patient went into cardiopulmonary arrest and was resuscitated and intubated with difficulty. The patient was admitted to intensive care and died 3 days later. (It was unclear from documentation whether this was a withdrawal of interventions.) One of the patient's parents remained in denial about the patient's low chances of recovery and survival and blamed the other parent for the patient's death.</p>