

ADVANCE CARE PLANNING WITH ADOLESCENT AND YOUNG ADULT STEM CELL
TRANSPLANT PATIENTS

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Abstract

Background: Advance care planning is not routinely performed with adolescent and young adult hematopoietic stem cell transplant patients, despite their critically ill status and the possibility that immediate medical decisions will need to be made on their behalf. The lack of advance care planning discussions or documentation can lead to incongruence between adolescent and young adult patients and caregivers about end-of-life preferences, poor communication between patients and providers, and unwanted medical interventions. Early initiation of advance care planning has been shown to be safe and feasible for adolescent and young adult patients facing life-threatening illnesses.

Local Problem: In the Blood and Marrow Transplant Division at a large, urban freestanding pediatric hospital in the mid-Atlantic, it was determined that advance care planning was not routinely introduced to adolescent and young adult hematopoietic stem cell transplant patients during the transplant process. The purpose of this quality improvement project was to implement a standardized procedure for the initiation of advance care planning discussions and completion of advance care planning documentation for adolescent and young adult patients ages 15 years and older undergoing allogeneic hematopoietic stem cell transplant.

Interventions: A standardized process for advance care planning meetings with adolescent and young adult patients was created, detailing procedures for identifying eligible patients, scheduling meetings for advance care planning during the pre-transplant process, and standardizing the documentation of advance care planning discussions. Five blood and marrow transplant team members participated in a one-hour training session conducted by a palliative care physician to increase knowledge and comfort level with advance care planning and the selected advance care planning document, Voicing My CHOICES™.

Results: Four eligible adolescent and young adult patients were admitted for transplant between October and December 2018. All four patients completed Voicing My CHOICES™ prior to hospital admission, and their completed documents were all easily located in the medical charts throughout their admissions. Documentation of the advance care planning discussion by the facilitating provider was present in the electronic health record for 100% of the patients. One hundred percent of the blood and marrow transplant team members rated the training session as “very helpful,” and rated Voicing My CHOICES™ as helpful, easy to use, and appropriate for adolescent and young adult stem cell transplant patients.

Conclusions: Early introduction of advance care planning is feasible for adolescent and young adult hematopoietic stem cell transplant patients. A standardized process for advance care planning helped to increase the number of adolescent and young adult hematopoietic stem cell transplant patients who participated in advance care planning discussions and completed Voicing My CHOICES™. This approach has the potential to improve communication and increase congruence between patients, caregivers, and providers.

Advance Care Planning with Adolescent and Young Adult Stem Cell Transplant Patients

Adolescent and young adult (AYA) patients, classified as those between 15 and 39 years old, who undergo hematopoietic stem cell transplants (HSCT) face extensive biopsychosocial challenges related to their life-limiting diagnoses, prolonged medical treatments, and numerous side effects (Duncan, Clark & Silverman, 2013). Overall survival rates after allogeneic HSCT have improved, but high-dose chemotherapy, radiation, and immunotherapy preparative regimens can cause life-threatening complications and substantial treatment-related morbidity, including overwhelming infection, graft-vs-host disease, and end organ damage (Needle & Smith, 2016). Despite their critically-ill status, the unpredictability of serious complications, and the possibility that immediate medical decisions will need to be made on their behalf, less than 25% of AYA patients have documented advance directives (AD) on admission for HSCT (Needle & Smith, 2016). The lack of advance care planning (ACP) discussions or documentation can lead to incongruence between AYA patients and caregivers about end-of-life (EOL) preferences, poor communication between patients and providers, and most distressingly, unwanted medical interventions (Lyon, Jacobs, Briggs, Cheng, & Wang, 2014; Needle & Smith, 2016). Research has shown that AYA patients prefer to be involved in EOL decisions even when death is not imminent (Jacobs et al., 2015; Lotz, Jox, Borasio, & Fuhrer, 2013; Lyon et al., 2014). However, ACP decisions are often made late in the treatment process (Needle & Smith, 2016; Ulrich et al., 2010). The early initiation of ACP using a standardized approach has been shown to be safe and feasible for AYA patients with life-threatening illnesses (Lyon et al., 2014; Wiener et al., 2012).

At a large, urban, academic children's hospital in the mid-Atlantic, the only patients who are legally required to have ADs during hospital admission are those above 18 years old. For

patients who are younger than 18 years of age, there was no process in place for completing ACP prior to HSCT (K. Lyons, personal communication, November 8, 2017). The purpose of this DNP project was to create and implement a standardized process for initiation of ACP discussions and completion of ACP documentation for AYA patients undergoing HSCT. The short-term goals of the project included creating a standard operating procedure (SOP) for the Division of Blood and Marrow Transplantation (BMT) that delineated the process of scheduling and conducting advance care planning discussions with eligible patients, training five HSCT providers (four advance practice providers (APP) and one social worker (SW)), on ACP and the new SOP, increasing provider comfort level with conducting ACP discussions, and completing an ACP document for at least one AYA patient undergoing HSCT. The long-term goals of the project were to standardize the process for initiating ACP discussions, and to increase the completion of ACP documents for AYA patients who were admitted for HSCT.

Theoretical Framework

The Knowledge to Action (KTA) Framework was developed by Graham et al. (2006) to synthesize knowledge generated by research and facilitate its application to clinical practice in order to improve patient care. The KTA Framework is separated into two phases: knowledge creation and action (Graham et al., 2006). While the two phases are different processes, the authors acknowledge that the phases often interact with and influence each other. Knowledge creation describes the process of identifying existing knowledge, appraising and analyzing it, and creating tools or guidelines for clinical practice (Graham et al., 2006). Throughout this phase, knowledge moves through a “funnel,” which helps to extract the most relevant research and adapt it to different users and contexts (Graham et al., 2006). The action cycle, which constitutes the implementation phase, consists of seven steps that are necessary for the practical application

of knowledge (Graham et al., 2006). After a problem is identified and the current evidence is assessed, the synthesized knowledge is modified to the local environment. Barriers and facilitators to knowledge utilization in the chosen setting are evaluated so that targeted translation strategies can be developed to promote the successful adoption of the intervention. After implementation, the knowledge use is observed, monitored, and evaluated in order to measure its impact and effectiveness. Finally, methods for sustaining the knowledge use must be determined to ensure the longevity of its results (Graham et al., 2006).

The KTA Framework was used to devise and guide the implementation plan for standardizing the ACP process and improving ACP documentation. The knowledge creation process described by the KTA encourages the utilization of experiential knowledge in addition to research-based knowledge. For a subspecialized population with limited available data, the ability to integrate expert opinions and descriptive studies was essential. The emphasis on both local and global knowledge, and the incorporation of context were especially relevant to this DNP project. Common challenges to initiating ACP discussions with AYA patients (provider discomfort, perceived unwillingness among patients) have been identified in the literature, and the implementation site was thoroughly assessed for the presence of these barriers. Because provider discomfort was identified as a local barrier, ACP training was incorporated into the implementation plan. Facilitators and early adopters were identified and employed to help propagate the intervention. The KTA Framework encourages the frequent reassessment of the barriers, facilitators, and intervention methods, which occurred at several points during the implementation period. Finally, a sustainability plan, including expanding provider training and creating a location for ACP documentation within the electronic health record (EHR), was developed to reinforce the new process and maintain stakeholder adherence.

Literature Review

The focus of this literature review is on the feasibility and effectiveness of ACP for AYA patients prior to HSCT. The review will begin with evidence supporting the desire of AYA patients to participate in ACP, and continue with evidence for the early initiation of those discussions. Finally, the review will conclude by highlighting findings that ACP increases the completion of AD. A more detailed summary of the evidence is provided in Appendix A.

The desire of AYA patients to participate in ACP has been examined by several different investigators. Jacobs et al. (2015) conducted surveys of 34 AYA patients with cancer who completed an ACP program for teens with cancer and found that 75% of adolescents considered it appropriate to discuss EOL decisions at any time, even when death was not imminent. Furthermore, while 82% of AYA patients found it important to talk about EOL decisions with their families, 53% had never discussed EOL preferences (Jacobs et al., 2015). ACP programs have been found to be helpful to both AYA patients and their families in starting those EOL discussions. Lyon, Jacobs, Briggs, Cheng, & Weng (2014) designed a two-armed RCT of 30 patients to evaluate the feasibility and acceptability of a pediatric ACP intervention for adolescents with cancer. The researchers discovered that a family-centered ACP program was deemed worthwhile by 82% of adolescents and 100% of their families. Likewise, Wiener et al. (2012) surveyed 52 AYA patients with either metastatic cancer or HIV to compare two ACP guides, and reported that 87% of AYA patients described all items on an ACP document as “helpful.” The hesitation to introduce ACP to AYAs often stems from a belief that patients will be unwilling or unable to contribute to EOL decisions (Jacobs et al., 2015); however, the existing research clearly demonstrates the strong inclination of AYA patients to participate in early ACP with their families and health care providers. While these studies examined AYA patients with

cancer or HIV, the results can be extrapolated to AYA patients undergoing HSCT, especially since many of those patients are being treated for relapsed cancer or other life-limiting diseases.

Although both AYA patients and families found it important to have discussions about EOL care, several teams of researchers found that ACP does not occur routinely or occurs late in treatment, especially among HSCT patients. In a retrospective chart review of 96 AYA patients undergoing HSCT, Needle and Smith (2016) discovered that only 23% of patients had a documented AD before or during HSCT admission, and that only 50% of those patients who died had an AD. Similarly, Ulrich et al. (2010) examined the EOL experiences among 141 pediatric cancer patients using semi-structured surveys and retrospective chart reviews, and found that resuscitation status was discussed significantly later in the group undergoing HSCT than in the non-HSCT group and resulted in fewer DNR orders written in the HSCT group. Even when goals of care are routinely discussed, ACP is not often incorporated into the conversations. Using retrospective chart reviews of 147 pediatric patients who underwent HSCT from 2004 to 2012, Ulrich et al. (2016) found that during palliative care meetings goals of care and decision making were discussed in 92% of cases, but ACP was discussed in only 22% of cases. While surveys and chart reviews provide low-level evidence, the nature of the subject matter and the specialized population often preclude large experimental trials with randomization. Thus, despite the threats to internal validity in these studies, it is readily apparent that ACP occurs far too late in the treatment process, and that AYA patients prefer early discussions regarding EOL care.

A standardized approach to ACP not only leads to its earlier initiation, it also increases the completion and documentation of ADs. In a systematic review of five qualitative studies and eight quantitative studies from 1991-2012, Lotz, Jox, Borasio, and Fuhrer (2013) assessed the current practices and effects of pediatric ACP, and the perceptions of ACP by patients, families,

and providers. They concluded that pediatric ACP programs encouraged the completion of ADs and promoted discussions of future medical interventions. In the previously described RCT by Lyon et al. (2014), the researchers implemented an ACP program for adolescents with cancer and reported that ADs were found in the medical charts of 100% of the intervention group as opposed to 0% of the control group. Encouragingly, ADs were still easily located in the medical records three months post-intervention. While the sample size was fairly small, the randomization of the participants and the inclusion of a control group significantly improved the validity of the results. Although Lotz et al. (2013) did not solely include studies on AYA HSCT patients, the data from the systematic review conveys strong support for the effectiveness of ACP in increasing AD documentation which can be generalized to the target population of this project. Through a careful analysis and synthesis of the literature, it is evident that the early introduction of ACP for AYA patients would be feasible, beneficial, and effective in increasing the completion of ACP documents prior to hospital admission for HSCT.

Implementation

Description of Project, Sample, Setting

This quality improvement (QI) project was intended to implement a standardized process for initiating ACP discussions and completing ACP documents for AYA patients undergoing HSCT. Through discussions with key stakeholders within the BMT department, it was determined that ACP was not routinely introduced to AYA HSCT patients during the transplant process (S. Ahmed-Winston and K. Lyons, personal communication, November 8, 2017).

Voicing My CHOICES™ is an advance care planning guide created using input from AYA participants to help young people living with serious illnesses to convey their EOL wishes and preferences to their families or caregivers (Appendix B). Voicing My CHOICES™ is available

to the public through the nonprofit organization Aging with Dignity, and was utilized as the standard ACP document in this project.

The project was implemented in the BMT department at a large, urban freestanding pediatric hospital in the mid-Atlantic. The 11-bed inpatient BMT unit is part of the larger hematology/oncology care unit. The sample population included AYA patients 15 years and older who were undergoing workup for allogeneic HSCT between October and December 2018. Inclusion criteria were patients 15 years and older, patients receiving allogeneic HSCT, and the ability to understand and speak English. Exclusion criteria were patients receiving autologous HSCT, patients with developmental or cognitive delays, patients who did not speak English, and participation in a concurrent ACP study. Based on data from the previous five years at this institution, it was estimated that one to four eligible patients would be undergoing HSCT workup during the implementation period.

Procedures and Timeline

The project was implemented over a 14 week period from September to December 2018. During weeks one and two, meetings were held with key stakeholders including the BMT APPs, SW, psychologist, and palliative care team to gather information and expert opinions about the pre-transplant timeline and the incorporation of ACP meetings. The project was presented to the BMT Policy and Procedure committee, and meetings were held with the BMT quality assurance coordinator to review the process for the creation and approval of departmental standard operating procedures (SOP). During weeks three and four, a preliminary SOP was developed with the guidance of the BMT APPs to outline the identification of eligible patients, the scheduling of pre-transplant ACP consultations and discussions, and the management of ACP documentation. The stem cell pre-transplant checklist, which functions as the guideline for

scheduling clinical appointments and consultations for patients during the transplant workup process, was updated to include ACP meetings (Appendix C). Meetings were held with the BMT schedulers to review the new checklist and scheduling procedure. During week five, ACP training for members of the BMT team was developed with a board-certified palliative care nurse practitioner (NP). The hour-long training session was held during week six, and conducted in conjunction with a palliative care team physician. Five BMT team members – four APPs and one SW- participated in the training session. A detailed lesson plan with learning objectives is included in Appendix D. The BMT team members were given pre-training surveys (Appendix E) and post-training surveys (Appendix F) to measure their comfort with ACP, effectiveness of training, and attitudes toward Voicing My CHOICES™. From week six (post-training) through week fourteen, ACP was available for all eligible AYA patients being admitted for HSCT. During week 10, meetings were held with the BMT APPs and SW to identify facilitators and barriers to the project implementation, and revisions were made to the SOP. During week 12, the revised SOP (Appendix G) and the updated checklist (Appendix C) were formally presented to the BMT Policy and Procedure committee for approval.

Data Collection

Pre-training and post-training provider data were collected using paper surveys. The surveys were adapted from Lyon et al. (2014) and utilized with verbal permission by Dr. Maureen Lyon (M. Lyon, personal communication, June 6, 2018). Weekly audits were conducted to identify the number of eligible patients admitted, the status of the ACP document (complete vs. incomplete), locations of the completed document, and the presence of EHR documentation of ACP discussion by the facilitating provider (Appendix H). At the time of

project implementation, there were no eligible AYA patients undergoing transplant workup, so audits were not performed to determine adherence to the new scheduling process.

Data Analysis

Provider comfort with and knowledge of ACP were analyzed using descriptive statistics. Mean scores of provider responses on the pre-training and post-training surveys were compared to assess the effectiveness of training. Frequency statistics were calculated to determine adherence to the new ACP process, operationalized as the numbers of eligible patients who were offered ACP discussions, completed ACP documents, properly located ACP documents, and EHR documentation of ACP discussion.

Protection of Participants

Participation in this QI project was voluntary. Patients and caregivers who did not want to complete Voicing My CHOICES™ were not required to participate. Psychosocial support, including psychologists, child life specialists, social workers, and a hospital-wide palliative care team, were readily available to patients and families. All data collected from participants, including both patients and members of the health care team, were de-identified and coded to maintain confidentiality. The data were stored in files on the organization's server, which required a verified login and password to access. The project proposal was approved by the University of Maryland Baltimore (UMB) Institutional Review Board (IRB) for a Non-Human Subjects Research determination. Additionally, the proposal was approved by the Nursing Research Advisory Committee and the IRB committee at the implementation site.

Sustainability Plan

There are several important ways to promote the sustainability of this project. ACP training should be extended to more BMT providers, and additional interdisciplinary team

members should be involved, including chaplains, psychologists, registered nurses, and child life specialists. Continued educational sessions will be held with the BMT schedulers, APPs, and physicians to review the new pre-transplant checklist and scheduling process for ACP meetings.

Finally, there should be a designated location in the EHR to upload and store completed ACP documents. The palliative care team at the implementation site is currently working to create a location for ADs in the EHR, which will facilitate the creation of an electronic folder for ACP documents. Additionally, a flag could be placed in the EHR to alert the BMT provider of patients who have missing or incomplete ACP documentation. In the future, ACP documents should be embedded within the EHR, allowing for improved accessibility, secure storage, and efficient revisions.

Results

Practice Changes

ACP is now being offered to all eligible AYA patients who are undergoing HSCT, starting with the pre-transplant workup evaluation and continuing through the transition to outpatient care. An SOP was created (Appendix G), and is undergoing approval. The stem cell transplant checklist has been updated to include ACP meetings (Appendix C), and the modified checklists are now uploaded on the BMT department's shared drive for provider access.

Data Analysis and Outcomes

Descriptive statistics were calculated for the sample of BMT team members ($n = 5$) who completed ACP training (Table 1). Eighty percent of the participants were APPs, and the majority had been in practice for less than five years. Provider attitudes regarding ACP were surveyed before and after training using a five-point Likert-type scale (1 = strongly disagree, 5 = strongly agree), and the mean scores of provider responses were compared (Table 2). Both

before and after training, 100% of the participants “strongly agreed” that ACP is useful. The majority of providers found ACP to be stressful both pre-training and post-training, though mean scores decreased slightly from 4 to 3.8. Responses to “advance care planning is uncomfortable” did not change with training ($\bar{X} = 3.8$). Familiarity with Voicing My CHOICES™ improved from pre-training ($\bar{X} = 3.6$) to post-training ($\bar{X} = 4$). Provider comfort with ACP discussions also improved after training, with mean scores increasing from 3.4 to 4. Post-training surveys were also conducted to measure provider attitude toward the training and Voicing My CHOICES™ (Table 3). One hundred percent of participants rated the training as “very helpful.” One hundred percent of participants “agreed” or “strongly agreed” that Voicing My CHOICES™ was helpful, easy to understand, easy to use, and appropriate for this patient population.

Four eligible AYA patients were admitted to the BMT unit between October and December 2018. One hundred percent of eligible patients completed Voicing My CHOICES™ prior to hospital admission, and the completed documents were all easily located in the medical charts throughout their admissions (Table 4). Documentation of the advance care planning discussion by the facilitating provider was present in the EHR for 100% of the patients.

Observed Associations

Due to the lengthy pre-transplant workup process beginning eight weeks in advance of the anticipated transplant, every eligible AYA patients admitted during the project implementation period had been previously scheduled for meetings and consults. Therefore, ACP meetings for these patients could not be scheduled according to the timeline delineated in the new SOP. However, ACP meetings were successfully conducted due to delegation from the primary APP to interdisciplinary BMT team members, which also fostered the completion and correct storage of Voicing My CHOICES™.

Unintended Consequences

The early initiation of pre-transplant evaluations and meetings was problematic for a project with a short implementation period. Additionally, the frequency of last-minute transplant delays due to abnormal labs or unforeseen illnesses was an unexpected barrier that affected several AYA patients during the implementation period. However, the consistent emphasis on advance care planning for AYA patients has increased awareness and renewed interest among the BMT providers. While the full scheduling process has not been fully implemented yet, ACP meetings are still being consistently conducted, and ACP documentation is being completed. After project conclusion, a BMT APP was able to coordinate with the palliative care team, psychologist, and language services to facilitate several ACP discussions and ACP document completion for an Arabic-speaking AYA patient undergoing workup for a very high-risk transplant.

Discussion

This QI project provided support for the feasibility and effectiveness of a standardized process for advance care planning with AYA HSCT patients. Prior to the intervention, there was no time allotted for ACP, and no provider directly responsible for its completion. Subsequently, ACP discussions were rarely held pre-emptively, and they were not routinely done during the pre-transplant process. By assigning one primary provider to complete ACP meetings, and appointing one BMT team member to manage the storage of ACP documents, the ACP process was successfully completed for each eligible patient. The SOP was not officially enacted during the implementation period; consequently, many of the pre-transplant meetings had already been completed and ACP meetings could not be scheduled according to the specified timeline. However, ACP discussions were still conducted for each eligible AYA patient due to delegation

by the primary provider and collaboration with the interdisciplinary psychosocial team, most notably the BMT social worker.

ACP training was found to be very helpful to providers, as well as effective at increasing provider comfort levels with conducting ACP conversations. Providers did not report a need for further ACP training after the one hour education session, suggesting that even a small amount of training can be effectual. With increased awareness of the importance of ACP for this patient population, earlier identification of eligible patients, and a designated provider responsible for its completion, ACP was successfully incorporated into the standard pre-transplant evaluation process.

Much of the existing research on ACP with AYA patients has focused on patient and caregiver attitudes toward ACP and congruency of EOL decisions, which were not examined during this project. However, the outcomes of this initiative reinforce the findings of several of the previously described studies. In particular, all of the AYA patients included in this project had copies of ACP documents easily located in their medical charts and on the department shared access drive, which echoes the results of Lyon et al. (2014). Additionally, the universal completion of ACP discussions and documentation during the implementation period demonstrates the feasibility of ACP with AYA patients, and the willingness of these patients to participate in ACP, reflecting the findings of Jacobs et al. (2015), Lyon et al. (2014), and Wiener et al. (2012).

This project had several strengths, most importantly the strong support from key stakeholders within the BMT department, psychosocial team, and the palliative care team. Furthermore, the multi-disciplinary effort and successful collaboration between the BMT APPs, BMT social worker, psychologist, and palliative care team were imperative in coordinating and

completing the ACP meetings. As a large and pediatric-focused hospital, the implementation site had many resources that contributed to the successful implementation of this initiative, including an existing palliative care team that was already closely involved with HSCT patients. Finally, this project utilized a previously validated and AYA-specific ACP guide. While several other ACP guides exist, Voicing My CHOICES™ is the only document that was created using AYA patient contributions, which was an important component of this project.

There were several limitations to this project, the most significant of which was the small sample size with only English-speaking patients. The implementation period was short and occurred during the fall and winter when fewer transplants were scheduled, both of which contributed to the small sample size. There were several delayed transplants due to patient condition, medical procedure, or further consultation that also decreased the sample size. Although the sample size was relatively small in comparison to other QI projects, it was consistent with the anticipated sample size. The SOP was created to offset the limited number of AYA HSCT patients admitted during the implementation period, and to establish a process for future AYA patients. Another major limitation was the existing pre-transplant process, which typically begins eight weeks before the anticipated admission date. Because of the early initiation of scheduling and evaluations, many of the eligible patients who were admitted after the provider training had been previously scheduled for workups in August and September. Finally, there is limited generalizability to patients outside of this setting as this project was designed to meet the needs of this specific unit.

Conclusion

Early introduction of ACP is feasible and effective for AYA HSCT patients. A standardized process led to increased patient participation in ACP, increased completion and

availability of ACP documents, and increased EHR documentation of ACP discussions. Voicing My CHOICES™ was found to be easy to use and appropriate for AYA HSCT patients by the BMT APPs and social worker. This approach can be an effective way to increase the frequency of ACP discussions and documentation, which has the potential to improve communication and increase congruence between patients, caregivers, and providers.

The updated stem cell transplant checklist (Appendix C) is now available to the BMT providers, and the BMT schedulers have been utilizing it to schedule ACP meetings as appropriate. The SOP is undergoing formal approval by the department, which will support the sustainability and longevity of the project. The ACP process is currently being adapted by the oncology team for utilization with AYA patients who have solid tumors, with the goal to expand to patients with other oncologic diagnoses and life-limiting hematologic diseases. ACP should also be considered for AYA patients with other chronic and life-limiting illnesses, such as cystic fibrosis, muscular dystrophy, or chronic kidney disease.

Further research is needed on AYA patient experience with ACP and Voicing My CHOICES™ and caregiver satisfaction. Additional ACP trainings should be planned to include more BMT providers, as well as the hematology and oncology providers. More effort should be made to involve patients who are non-native English speakers, including the training of bilingual providers, the translation of Voicing My CHOICES™ into other languages, and collaboration with the global services department to ensure culturally sensitive ACP conversations. Finally, integration of ACP documentation into the EHR should be prioritized to facilitate the continued success of ACP with AYA patients.

References

- Duncan, C. N., Clark, J. J. & Silverman, L. B. (2013). Hematopoietic stem cell transplantation in unique pediatric populations: Adolescents, infants, and children with down syndrome. *Biology of Blood and Marrow Transplantation*, *19*(1), S52-S57. doi: 10.1016/j.bbmt.2012.10.018.
- Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W. & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *The Journal of Continuing Education in the Health Professions*, *26*(1), 13-24.
- Jacobs, S., Perez, J., Cheng, Y. I., Sill, A., Wang, J., & Lyon, M. (2015). Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer. *Pediatric Blood & Cancer*, *62*(4), 710-714. doi: 1002/pbc.25358
- Lotz, J. D., Jox, R. J., Borasio, G. D., Fuhrer, M. (2013). Pediatric advance care planning: A systematic review. *Pediatrics*, *131*(3), e873-880. doi: 10.1542/peds.2012-2394
- Lyon, M. E., Jacobs, S., Briggs, L., Cheng, Y. I., & Wang, J. (2013). Family-centered advance care planning for teens with cancer. *JAMA Pediatrics*, *167*(5), 460-467. doi: 10.1001/jamapediatrics.2013.943.
- Lyon, M. E., Jacobs, S., Briggs, L., Cheng, Y. I., & Wang, J. (2014). A longitudinal, randomized, controlled trial of advance care planning for teens with cancer: Anxiety, depression, quality of life, advance directives, spirituality. *Journal of Adolescent Health*, *54*(6), 710-717. doi: 10.1016/j.jadohealth.2013.10.206
- Needle, J. & Smith, A. R. (2016). The impact of advance directives on end-of-life care for adolescents and young adults undergoing hematopoietic stem cell transplant. *Journal of Palliative Medicine*, *19*(3), 300-305. doi: 10.1089/jpm.2015.0327

- Ullrich, C. K., Lehmann, L., London, W. B., Guo, D., Sridharan, M., Koch, R. & Wolfe, J. (2016). End-of-life care patterns associated with pediatric palliative care among children who underwent hematopoietic stem cell transplant. *Biology of Blood and Marrow Transplantation*, 22(6), 1049-1055. doi: 10.1016/j.bbmt.2016.02.012.
- Ullrich, C. K., Dussel, V., Hilden, J. M., Sheaffer, J. W., Lehmann, L., & Wolfe, J. (2010). End-of-life experiences of children undergoing stem-cell transplantation for malignancy: Parent and provider perspectives and patterns of care. *Blood*, 115(9), 3879-3885. doi: 10.1182/blood-2009-10-250225.
- Wiener, L., Zadeh, S., Battles, H., Baird, K., Ballard, E. Osherow, J., & Pao, M. (2012). Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics*, 130(5), 897-905. doi: 10.1542/peds.2012-0663

Table 1

Pre-Training Survey Results

	N (%)
What is your clinician role?	5
Advance Practice Provider	4 (80)
Social Worker	1 (20)
How many years have you practiced your discipline?	5
< 5 years	3 (60)
6-11 years	1 (20)
11-20 years	1 (20)
How much training have you had in facilitating advance care planning?	5
None	1 (20)
A little	1 (20)
Some	3 (60)
During the past 3 years, how many patients have you cared for who have died?	5
<5	1 (20)
6-10	3 (60)
10-20	1 (20)
During the past 3 years, how many times have you regretted not having a discussion with a patient about advance care planning?	5
<5	4 (80)
6-10	1 (20)

Table 2

Provider Attitudes Regarding Advance Care Planning

Survey Questions	Pre-Training		Post-Training	
	N (%)	Mean	N (%)	Mean
Advance Care Planning is Useful 5= strongly agree	5 5 (100)	5	5 5 (100)	5
Advance Care Planning is Necessary 5 = strongly agree 4 = agree	5 4 (80) 1 (20)	4.8	5 5 (100)	5
Advance Care Planning is Stressful 5 = strongly agree 4 = agree 2 = disagree	5 2 (40) 2 (40) 1 (20)	4	5 1 (20) 3 (60) 1 (20)	3.8
Advance Care Planning is Uncomfortable 5 = strongly agree 4 = agree 3 = neutral 2 = disagree	5 2 (40) 1 (20) 1 (20) 1 (20)	3.8	5 1 (20) 3 (60) 0 1 (20)	3.8
I am familiar with the advance care planning guide Voicing My Choices 5 = strongly agree 4 = agree 3 = neutral 2 = disagree	5 1 (20) 2 (40) 1 (20) 1 (20)	3.6	5 1 (20) 4 (80)	4
I feel comfortable discussing advance care planning with my patients 4 = agree 3 = neutral	5 2 (40) 3 (60)	3.4	5 5 (100)	4
I wish I had more training on advance care planning 5 = strongly agree 4 = agree 3 = neutral 2 = disagree	5 2 (40) 3 (60) 0 0	4.4	5 0 2 (40) 2 (40) 1 (20)	3.2

In your opinion, when is the best time to bring up end-of-life decisions? Select all that apply.	5	5
Before getting sick, while healthy	1 (20)	2 (40)
When first diagnosed with a life-threatening illness	2 (40)	3 (60)
When first sick from a life-threatening illness		
When first hospitalized with a life-threatening illness		
If dying		
Never		
All of the above	2 (40)	1 (20)
Don't know		

Table 3

Post-Training Provider Attitudes Regarding Training and Voicing My CHOICES™

	N (%)	Mean
Was the training provided helpful to you?	5	5
Very Much	5 (100)	
Who do you think is/are the best person/people on the treatment team to bring up end-of-life decisions with a patient? Select all that apply.	5	
Physician	5 (100)	
Advance Practice Provider	5 (100)	
Registered Nurse	3 (60)	
Social Worker	5 (100)	
Psychologist	5 (100)	
Child Life Specialist	3 (60)	
Case Manager	1 (20)	
Chaplain	3 (60)	
Voicing My CHOICES™ is helpful	5	4.4
5 = strongly agree	2 (40)	
4 = agree	3 (60)	
Voicing My CHOICES™ is easy to understand	5	4.4
5 = strongly agree	2 (40)	
4 = agree	3 (60)	
Voicing My CHOICES™ is easy to use in leading an advance care planning discussion	5	4.4
5 = strongly agree	2 (40)	
4 = agree	3 (60)	
Voicing My CHOICES™ is appropriate for this patient population	5	4.6
5 = strongly agree	3 (60)	
4 = agree	2 (40)	

Table 4

Chart Audit Results

Patient Code	Voicing My CHOICES™ Completed	EHR Documentation of ACP Discussion	Voicing My CHOICES™ hard copy located in patient's chart	Voicing My CHOICES™ uploaded to BMT shared access drive	Voicing My CHOICES™ easily located at patient discharge
75	1	1	1	1	1
12	1	1	1	1	1
98	1	1	1	1	1
46	1	1	1	1	1

0 = No

1 = Yes

Appendix A
Evidence Rating Table

Author, Year	Study Objective/ Intervention	Design	Sample (n)	Outcomes Studied (how measured)	Results	Level and Quality Rating
Jacobs et al. (2015)	<p>To determine the baseline agreement between the self-reported wishes of AYA cancer patients for end of life (EOL) care and their families' understanding of their wishes</p> <p>Family-Centered Advance Care Planning for Teens with Cancer (FACE-TC) program vs. treatment as usual with an educational brochure about advance care planning</p>	Surveys conducted by trained facilitators of patients and families in the intervention arm of a study by Lyon, Jacobs, Briggs, Cheng, & Wang (2014); post-study survey of providers of the participants	34 adolescents with cancer and family members (17 dyads); patients were between 14 and 21 years old and randomized into the intervention FACE-TC group or the standard of care control group	<p>Congruence between adolescent EOL preferences and their parents' perceptions of those preferences</p> <p>Lyon Advance Care Planning Survey-Adolescent and Family Versions, a 31-item survey with responses measured on a 5-point Likert scale, was separately administered to adolescents and their surrogates by trained facilitators</p> <p>Provider survey with 3 sections: demographic/career, interaction with FACE-TC study, optional section about personal experiences with EOL care</p>	<p>Almost perfect agreement between adolescents and parents about "understanding treatment choices" (Kappa 0.88), "being physically comfortable" (Kappa 0.88), "being free from pain" (Kappa = 0.88)</p> <p>Slight agreement between adolescents and parents about "dying a natural death" (Kappa = 0.09)</p> <p>Less than chance agreement between adolescents and parents about "dying at home" (Kappa = -0.06) and "Wanting to know if I were dying" (Kappa = -0.04)</p> <p>75% of adolescents considered it</p>	II C

					<p>appropriate to talk about EOL decisions at any time, not just “if dying”</p> <p>65% of adolescents preferred to die at home, but 88% had not heard of hospice care</p> <p>71% had never heard of or completed an advance directive (AD)</p> <p>82% found it important to discuss EOL wishes with family, but 53% had never discussed EOL preferences</p> <p>46% of providers believed that patients under 18 years old who were willing and able should always complete an AD; 80% believed this for patients over 18 years old</p> <p>83% of providers believed the FACE-TC study was “somewhat” or</p>	
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					<p>“very much” helpful to their patients 78% of providers believed participation in the FACE-TC study was “somewhat” or “very much” helpful to themselves</p> <p>Providers felt that having an AD document was beneficial for patient communication</p>	
Lotz, Jox, Borasio, & Fuhrer (2013)	To identify current practices and effects of pediatric advance care planning (ACP)	Systematic review using the PRISMA checklist as basis for the process	5 qualitative studies and 8 quantitative studies published between 1991 and 2012	<p>Frequency of pediatric ACP</p> <p>Main elements of pediatric ACP programs</p> <p>Participants of pediatric ACP</p> <p>Effects of pediatric ACP</p> <p>Perceptions of pediatric ACP by patients, families/surrogates, and health care providers</p>	<p>Only 3 pediatric ACP programs were identified in the United States</p> <p>3 studies show that pediatric ACP programs encourage the completion of AD</p> <p>2 studies show that pediatric ACP programs promote parental discussion of future medical interventions</p> <p>2 studies demonstrate that pediatric ACP</p>	V C

					<p>increases home deaths for children</p> <p>1 RCT found that pediatric ACP participants had more positive emotions and fewer negative emotions after ACP discussions, reduced difficulties in making decisions about treatment, and felt more informed about their decisions</p> <p>2 studies found that pediatric ACP increased parental understanding of patient wishes, and was helpful in providing the best care</p> <p>3 studies showed that AYA patients did not report more distress with ACP discussions, felt comfortable talking about ADs, and preferred to have earlier conversations about EOL care</p>	
--	--	--	--	--	--	--

					1 study found that providers felt more prepared for ACP discussions after the initiation of an ACP program	
Lyon, Jacobs, Briggs, Cheng & Wang (2013)	Assess the effectiveness of family-centered advance care planning (ACP) using 3 sessions of facilitated conversations versus standard of care using an informational brochure	Two-group, randomized controlled trial	30 dyads made up of adolescents with cancer aged 14-21 years old and their legal guardians (or surrogate decision makers) who were treated at a pediatric oncology program in Washington, D.C. between January 2011 and March 2012	Statement of treatment preferences administered to adolescents and their surrogates Decisional Conflict Scale administered to adolescents during study visit 3 after completion of statement of treatment preferences Quality of Participant-Interviewer Communication administered separately to adolescents and surrogates during study visits 2, 3, and 4	Adolescents in intervention group significantly more informed about EOL decisions (p = .007) Treatment preference congruence was significantly increased for dyads in the intervention group (p < .001) for 4/6 of disease-specific scenarios Treatment preference congruence was low for the standard of care dyads, and there were no statistically significant results in any of the 6 scenarios 100% of adolescents in intervention group vs 62% of adolescents in standard of care	II C

					group (p = .009) agreed that their surrogates should “do what he/she thinks is best at the time, considering my wishes”	
Lyon, Jacobs, Briggs, Cheng, & Wang (2014)	<p>Evaluate the feasibility and acceptability of a pediatric advance care planning intervention for adolescents with cancer</p> <p>Family-Centered Advance Care Planning for Teens with Cancer (FACE-TC) program vs. treatment as usual with an educational brochure about advance care planning</p>	Two-armed, randomized, controlled trial	<p>30 adolescents age 14-21 years with cancer and 30 family members >21 years.</p> <p>Exclusion criteria: severe depression, suicide/homicide ideations, psychosis, placement in foster care, severe developmental delays, impaired mental status</p>	<p>Acceptability measured by the Satisfaction Questionnaire, a 13-item survey with a 5-point Likert scale</p> <p>Impact of FACE-TC measured using Pediatric Quality of Life Inventory 4.0 Generic Core Scale, the Pediatric Quality of Life Inventory 4.0 Cancer-Specific Module, the Beck Depression and Anxiety Inventories, the Spiritual Well-Being Scale of the Functional Assessment of Chronic Illness Therapy-IV</p> <p>Completion of advance directive using Five Wishes</p>	<p>FACE-TC was found to be feasible, safe, and acceptable to families with 72% of eligible families enrolled; 100% attendance at each study session, 93% retention 3 months post-intervention.</p> <p>100% of families and 82% of adolescents rated FACE-TC worthwhile</p> <p>Anxiety scores significantly decreased from baseline to 3 months post-intervention in both groups (p= .0212)</p> <p>FACE-TC group had significantly lower depression scores at baseline (p = .0268) and at 3 months post-</p>	II B

					<p>intervention than the control group</p> <p>No significant differences in quality of life scores between groups or over time</p> <p>Advance directives easily found in 100% of FACE-TC participants vs 0% in control group</p> <p>Advance directives easily found in medical records 3 months post-intervention</p>	
Needle & Smith (2016)	Assess the effect of advance directives (AD) on end of life (EOL) care among adolescent and young adult patients undergoing hematopoietic stem cell transplant (HSCT)	Retrospective chart review	96 HSCT patients between 14 and 26 years old treated at the University of Minnesota from April 2011 to January 2015	<p>EOL outcomes of patients indicating life-sustaining treatment (LST) in ADs, patients indicating no LST in ADs, patients who only named proxies in their ADs, and patients without ADs</p> <p>Receipt of life-sustaining treatment (LST) (positive pressure ventilation, mechanical ventilation, dialysis, CPR)</p>	<p>23% of patients had documentation of AD before or during HSCT admission</p> <p>50% of patients who died had an AD</p> <p>No significant differences in the provision of life-sustaining treatment (LST) in the ICU between patients with an AD calling for LST, patients designating proxies,</p>	VI C

				<p>Location of death</p> <p>Withholding or withdrawing or LST</p> <p>Length of stay in ICU</p> <p>Presence and timing of DNR orders</p>	<p>and patients without an AD</p> <p>Location of death significantly different based on AD choices. 100% of patients who wanted to limit LST died at home vs. 25% of patients who requested LST, identified a proxy only, or had no AD</p> <p>Among the patients who died in the ICU with a DNR order, none of the DNR requests came from the patients</p>	
Ulrich et al. (2010)	Describe the end of life (EOL) experiences of pediatric patients undergoing HSCT as treatment for cancer	Parent and physician surveys with a 390-item semi-structured question, retrospective chart review	<p>141 parents of children who died from cancer</p> <p>HSCT group n = 32 Non-HSCT group n = 110</p>	<p>Patterns of EOL care (location of death, resuscitation status, intubation in last 24 hours of life)</p> <p>Understanding of prognosis</p> <p>Goals of care</p>	<p>Resuscitation status discussion documented in chart with equal frequency between groups (HSCT 74%, non-HSCT 79%, p = .625)</p> <p>Resuscitation status discussion occurred significantly later in HSCT group than in non-HSCT group (p = .001), and resulted in fewer DNR orders written in HSCT group (p = .028)</p>	VI C

					Parents and providers were significantly more likely to recognize that children in the non-HSCT group (79%) had no realistic hope for cure within the last 7 days of life vs children in the HSCT group (42%) (p < .001)	
Ullrich et al. (2016)	Assess the effect of palliative care (PC) on end of life (EOL) outcomes of pediatric patients who received HSCTs and did not survive	Retrospective chart review	<p>147 pediatric patients who underwent HSCT at Boston Children’s Hospital/Dana Farber Cancer Institute between September 2004 and December 2012 and did not survive</p> <p>Children who received palliative care (n= 37)</p> <p>Children who did not receive palliative care (n =110)</p>	End of life care patterns for patients who received palliative care, including: details on death (cause, timing, location), EOL care (use of hospice, documentation of or receipt of resuscitation), documentation and timing of discussions related to prognosis or resuscitation status	<p>Discussions about resuscitation status were significantly more common in the PC group (PC 88%, non-PC 58%, p = .002)</p> <p>Discussions about resuscitation status occurred earlier before death (PC median 7 days before death, non-PC median 2 days before death, p < .001)</p> <p>Documentation of resuscitation status significantly more common in PC group (PC 97%, non-PC 68%, p = .002)</p> <p>During initial palliative care</p>	VI B

					consult meeting, goals of care/decision-making was discussed in 92% of cases and advance care planning was discussed in 22% of cases	
Wiener et al. (2012)	To compare the use of the advanced care planning guide My Thoughts, My Wishes, My Voice (MTMWMV) to the adult document Five Wishes by AYA patients with a serious illness	Survey to evaluate the helpfulness and stressfulness of each item within the two documents	52 patients between 16 and 28 years who were living with either metastatic cancer or HIV between 2008 and 2011	Readiness assessment to evaluate willingness to discuss EOL topics 5 point Likert-style questionnaire assessing the helpfulness and stressfulness of each item on the two documents, and the entirety of each document	54% preferred to complete MTMWMV, 37% preferred Five Wishes, 9% had no preference 94% rated all items as helpful, except "spiritual wishes" and "open letter," (which 87% rated as helpful) 81% rated "type of medical treatment" as most stressful	VI C

Appendix B
Voicing My CHOICES™

Voicing My **CHOICES**

I, _____, **ask**
that my family, my doctors, my friends, and my health care providers
follow my wishes as communicated in this booklet. This booklet is only
to be used in the case I can no longer communicate my wishes myself.

My SIGNATURE: _____

My Date of Birth: _____

Address: _____

Phone: _____ Today's Date: _____

Witness Statement:

I, the witness, declare that the person who signed or
acknowledged this booklet is known to me, that he/she signed this
booklet based on his/her own thoughts, wishes and desires, and that
he/she is of sound mind and no duress, or undue influence.

Signature of Witness # 1 _____ Signature of Witness # 2 _____

Printed Name _____ Printed Name _____

Address _____ Address _____

Notarization *(if required by the state you live in)*

Voicing My CHOICES

When living with a serious illness there are often things in life that are out of your control. *Voicing My CHOICES* gives you a way to express something very important – your thoughts about how you want to be comforted, supported, treated, and remembered.

This booklet was developed based on feedback from young people living with a serious illness. There are no right or wrong ways to answer the items in *Voicing My CHOICES*. You can complete as much or as little of this booklet as you would like. There are boxes to check if you agree with certain items, and there is also space to express your thoughts in your own words.

At the end of the booklet, there are some blank pages. On these pages, feel free to share any

additional thoughts and wishes not covered in this booklet. You can also use these pages to write a letter(s) to friends or family members.

Please keep in mind that the topics covered in this book can sometimes be difficult or confusing to think about. Your healthcare providers are available to help explain terms and/or procedures that you may not understand or may have questions about.

Additionally, there is a glossary of terms that may provide clarification for you on page 15. Any term **underlined in blue** throughout this booklet is defined in the glossary.

Contents

- My Signature, page 2
- My Comfort, page 4
- My Support, page 5
- My Medical Care Decisions, page 6
- My Medical Treatment, page 7
- My Family/Friends To Know, page 8
- My Spiritual Thoughts, page 9
- My Remembrance, page 10
- My Belongings, page 11
- My Voice (Letters), page 12
- Glossary, page 15

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Choose What Provides You the Most Comfort, Voice Your Thoughts and Needs

Stay What Makes You Feel Supported, Write What Decisions Bring You Peace

Contents	
My Signature,	page 2
My Comfort,	page 4
My Support,	page 5
My Medical Care Decisions,	page 6
My Medical Treatment,	page 7
My Family/Friends To Know,	page 8
My Spiritual Thoughts,	page 9
My Remembrance,	page 10
My Belongings,	page 11
My Voice (Letters),	page 12
Glossary,	page 15

Sometimes people can feel very uncomfortable when they are ill.
 For example, they might have pain, become sleepy or not feel like themselves. It is important for others to know how you want to be treated and what will make you feel more comfortable, especially if you become very ill and cannot express your wishes on your own.

How I Want To Be Comforted

My Voice

My favorite music/food is:

The kinds of books, stories, or readings I like, are:

Other thoughts I have about treating my pain, or helping to make me comfortable, are:

I would also like:

My Choice *These are a Few of the Comforts Important to Me*

If I look like I am uncomfortable in the following ways: *(Please check all that apply)*

I want treatment to help me, if I:

- Look sad
- Am irritable/frustrated
- Look nauseated
- Look confused
- Look like I am having a hard time breathing
- Am cold or hot

If I am in pain, I would like:

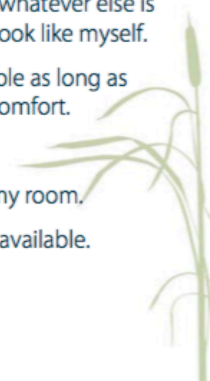
- My doctor to give me enough medicine to relieve my pain, even if that means I will not be awake enough to interact with my friends or family.

Or,

- To receive medications to reduce my pain but I do not want to be too sleepy or drowsy. I want to be awake enough to interact with my friends and family.

Other things that are important to me are:

- If I am not able to get to the bathroom in time, please change my clothes and sheets right away so that I am always clean.
- If friends are coming to visit, please dress me, comb my hair and do whatever else is needed to help make me look like myself.
- Massages whenever possible as long as they do not cause me discomfort.
- To be bathed.
- To have music playing in my room.
- To have my favorite foods available.
- To be read to.



Who I Want to Make My Medical Care Decisions If I Cannot Make Them On My Own

There might be a time when you cannot make medical decisions for yourself. If this happens, it might be necessary for someone else to speak with the doctors and make decisions about your medical care. This person, called a healthcare agent, would make sure that your thoughts or wishes are respected.

Things To Consider When Choosing a Healthcare Agent:

It can be helpful to choose someone who knows you well, cares about you, lives nearby, and can make difficult decisions. If you are under the age of 18, your parents/ guardians will have legal rights to make decisions, so the person you recommend can be your parents/guardian or someone you would like your parents/guardians to work with.

Remember:

- Your healthcare agent must be at least 18 years old.
- Your healthcare agent cannot be your doctor or any of your other health care providers, nor can it be an employee of any your health care providers.
- To talk to the people you are choosing to make sure that they agree to follow your wishes.

The person(s) I want to make healthcare decisions for me is/are:

Name	Name
Address	Address
Phone	Phone

If this person(s) I chose above are somehow unavailable, others who can make healthcare decisions for me are:

Name	Name
Address	Address
Phone	Phone

I give my health care agent permission to make these choices for me about my medical care or services.

(Please check all that apply)

To allow or refuse:

- Tests
- Medicines
- Surgeries
- Other care that can help keep me alive
- Medication(s) or procedure(s) to help with pain
- Stop previously started treatment
- Donate usable organs and/or tissue of mine if it can help others

Act on my behalf to:

- Hire and/or fire any health care worker I may need to take care of me
- See and approve release of my medical records
- Apply for **Medicaid, Medicare, or insurance benefits** for me
- See my personal files, like bank records, to access necessary information
- Perform any necessary legal action(s)

Arrange for:

- Hospital or **hospice** admission
- Admission to a facility in another state to get the care I need or to carry out my wishes
- Hospital discharge to take me home
- My healthcare agent is also allowed to make decisions based on conversation(s) we have had about my wishes and what he/she believes my wishes to be

Other things I wish my health care agent to do are:

The types of **Life Support Treatment** I Want, or Do Not Want

If a time comes when you are very ill and not able to speak for yourself, it will be important for your health care agent to know whether you would choose to try **life-support treatment**.

Life-support treatment means any medical procedure, device or medication used to try to keep you alive. It can include: medical devices put in you to help you breathe (**tracheotomy/mechanical ventilation**); an **artificial pacemaker** to help maintain your heart-beat; food and water supplied by medical device (**tube feeding**); **cardiopulmonary resuscitation (CPR)**; major surgery; **blood transfusions**; **dialysis**; **antibiotics**; **blood pressure medications** and anything else meant to keep you alive.

In place of life-support treatment, you may make the decision to allow a **natural death**, in which life-support treatments that prolong the dying process are not used, and everything possible is done to provide comfort and support.

If my doctor and another health care provider both decide that I am **close to death** and likely to die within a short period of time, and life support treatment would only delay the moment of my death:

- I want to have a natural death
- I want to try life support treatment if my doctor believes it could help my symptoms
- I want to try life support treatment no matter what

If my doctor and another health care provider decide that I have **permanent and severe brain damage** and I am not expected to get better, and life support treatment would only delay the moment of my death:

- I want to have a natural death
- I want to try life support treatment if my doctor believes it could help my symptoms
- I want to try life support treatment no matter what

Describe here if you want to have certain forms of life-support treatment, but not others, or if you wish to state other conditions in which you would want, or not want, life-support treatment:

Other decisions I would like respected:

In Case of An Emergency

If you have an event in which your heart stops beating or you stop breathing, you have the option to allow a natural death by indicating you would like a **Do Not Resuscitate (DNR) Order** to be written on your behalf. If you would like to try CPR, or advanced cardiac life support, it is important

that your health care agent and your medical team know. A DNR Order does not effect any treatment you would otherwise be getting. **Check with your doctor to talk more about the DNR Order.**

What I Would Like My Family and Friends to Know About Me

My Choice It is important to me that my family/friends:

- Get along
- Take care of themselves
- Take care of one another
- Respect my wishes, decisions and choices even if they don't agree with them
- Get counseling or find a support group for themselves and/or my siblings if they are having a hard time

My Voice

I want my family to know that I am thankful for their love and support. I am especially thankful for:

I want my friends to know that I am thankful for their love and support. I am especially thankful for:

If I have hurt or upset any of my friends, family or others, I wish to be forgiven for:

When I have been hurt or upset by my family, friends, or others, they should know I forgive them for:

These are the things that are important to know about me:

The things that give me strength are:

The things that give me joy are:

Not everyone has a religion or spiritual beliefs with which they feel connected. Others find great comfort in a faith or a belief system. On this page, you can write down your own thoughts on religion and spirituality, discuss your wishes and indicate what brings you the greatest comfort, in case you are not able to express these wishes for yourself.

My Spiritual Thoughts and Wishes

My Choice

- I would not like to have spiritual/religious activities incorporated into my care.
- I would like to have spiritual/religious activities incorporated into my care. *(Please check all that apply)*
 - I would like people to come pray with me.
 - I would like members of my religious/ spiritual community to be told about my illness and I would like them to pray for me.
 - I would like members of my religious/spiritual community to visit me.
 - I would like a hospital-based religious leader such as a chaplain, rabbi, priest or pastor to visit me while I am sick.
 - Every day
 - Once a week
 - Just when I ask

The words, music, and/or activities I find comfort from are:

My Voice

People from my religious community that I would like to come visit me are:

Based on my personal beliefs, I would like people to talk about death or the afterlife as:

The spiritual objects (such as prayer beads, holy books, or figurines) that I would like to have with me are:

Other spiritual thoughts or wishes that I would like to share with my family and/or friends:

How I Wish To Be Remembered

If it is more comfortable, you may choose to let others decide about a funeral, a memorial service, and caring for your body after death. Or you can use these pages to voice your preferences.

My Remembrance

- I prefer not to be a part of planning my service.
- I prefer to plan my service. *(Please check all that apply)*

The type of service(s) I would like are:

- Funeral**
- Memorial service**
- Celebration of my life**

I would like:

- To be **buried**
- To be **cremated**
- An **open casket**
- A **closed casket**

- To **donate my body** to science
- To be an **organ donor**

- A **limited autopsy**
- A **standard autopsy**
- A **research protocol autopsy**
- I would like my healthcare agent to make the autopsy decision

The clothes that I would like to be wearing (for service/cremation/burial) are:

The items that I would like to be with me are:

The music/food I want at my service are:

The people I would like to be present are:

I would like these readings at my service:

I would like these other arrangements at my service:

If my family or friends want to make contributions or donations I would like them to go to:



People in your life will always love you and think about you. There may be special ways that you want to distribute your belongings and be remembered, especially on certain days such as your birthday, holidays or any other day that is important to you. This is a page to detail any wishes that you have for how you would like to be remembered for the years after you are gone.

As with the other pages, take your time filling this out. Your family and friends will appreciate knowing what you desire and how you would like to be remembered so that they can fulfill your wishes and know that by doing so, they have your special approval.

This is How I Would Like To Share My Belongings:

My Belongings

Clothes: _____	Pets: _____
Games: _____	Books: _____
Art: _____	Music: _____
Photographs: _____	Phone: _____
Computer: _____	Other electronics: _____
Furniture: _____	Money/savings: _____
Other belongings: _____	

The person I would feel most comfortable going through my belongings is:

Special Days

How I would like to be remembered on my birthday:

How I would like to be remembered on other important days:

When people ask about me, please say the following:

My Voice

This is a space to **write**
messages
and/or letters to loved ones.

Lined writing area with a large orange 'SAMPLE' watermark and a decorative illustration of a plant and butterflies in the bottom left corner.

Glossary

Artificial Pacemaker

A small battery-operated mechanical device, which uses electrical impulses to keep the heart beating regularly. They can be internal (surgically implanted) or external (attached with wires to the skin). Pacemakers are usually only for temporary use.

Autopsy

A standard autopsy is a medical procedure that consists of a thorough examination of your body to determine the specific cause of death or to evaluate any disease or injury. There are 3 types of autopsies: 1) a limited autopsy (a specific part of the body or body system); 2) a full autopsy (studies most organs); and 3) a Research Protocol Autopsy (conducted for research purposes).

Blood Transfusion

The process of transferring blood or any of its components into the bloodstream of a person who has lost blood because of illness, an accident or surgery.

Body/Tissue Donation

You can choose to donate either your whole body, or some of your tissue for medical research and education after death.

Brain Damage

An injury to the brain caused by trauma to the head, infection, hemorrhage (bleeding), inadequate oxygen, or other complications, which results in significant loss in brain functioning or consciousness.

Burial

The act of placing a body into its final resting place. An urn or special container can be used to store remains from cremation.

Cardiopulmonary Resuscitation (CPR)

An emergency procedure performed on a person who has no pulse and has stopped breathing. CPR consists of external cardiac massage and artificial respiration (breathing) in an attempt to restore circulation of the blood and prevent death or brain damage.

Celebration of My Life

A gathering of your family/friends that is planned to honor and celebrate your life. Some choose to have a gathering yearly or just once after their death.

Closed Casket

When the casket is closed at a funeral so that those present do not view the body.

Coma

A state of unconsciousness, lasting more than 6 hours, in which a person cannot be awakened, fails to respond to external stimuli, including pain and light, lacks a normal sleep-wake cycle, and does not initiate voluntary actions.

Cremation

The process of reducing the body by intense heat. Cremated remains are typically placed in a container (urn) and can be placed or buried at memorial sites or kept by relatives/friends. If you choose to be cremated, it is still possible to have a viewing of your body (open casket) before the cremation process.

Dialysis

A medical treatment in which an artificial filtering system removes waste from the blood, performing the functions of the kidneys if they are not working.

Feeding Tubes

A medical device used to provide nutrition to patients who cannot obtain nutrition on their own.

Funeral

A ceremony used to mark a person's death. A person's body is typically at the funeral.

Healthcare Agent

The person chosen, legally named, or designated under state law to make healthcare decisions on behalf of a person who is no longer able to make his or her own decisions.

Healthcare Providers

A person or organization that provides healthcare in any way, including: doctors, nurses, administrators, and other staff who are affiliated with your care or your care facility.

Hospice

An organization or facility that provides care for the terminally ill focused on palliation (comfort) when curative treatment is no longer an option. Hospice care involves medical care, pain management, and emotional/spiritual support. It can be provided inpatient or outpatient and focuses on maintaining quality of life and symptom control.

Insurance

A program used to assist with costs of healthcare.

Insurance Benefits

Payments or compensation provided to assist with costs of healthcare.

Life-Support Treatment

Any treatments used to maintain the vital functions of the body in order to sustain the life of someone who is critically ill or injured.

Mechanical Ventilation

The medical procedure used to aid or replace breathing when someone is unable to breathe on his or her own. A machine called a ventilator forces air into the lungs via a tube that is inserted in the nose or mouth and down the windpipe.

Medicaid

A federal system of health insurance for those requiring financial assistance.

Medicare

A federal system of health insurance for people over age 65, or qualified young people with disabilities.

Natural Death

When life-support treatments are not used and everything possible is done to provide comfort and support.

Memorial Service

A service or ceremony performed to honor a deceased person. The body or cremated remains are typically not present. More than one memorial service can be held.

Open Casket

When the casket is left open during a funeral in order to allow for a viewing. A mortician at the funeral home will prepare and dress the body for viewing.

Organ Donation

The removal of the tissues (organs) of the body from a person who has recently died to a living recipient in need of a transplant.

Tracheostomy

A surgical operation that creates an opening into the trachea (windpipe) with a tube inserted to provide a passage for air in order to help someone breathe.

Appendix C
Updated Stem Cell Pre-Transplant Checklist

ALL/AML/CML Pre-Transplant Work-Up

Patient Name: _____ MR: _____
 DOB: _____ Disease Related Complications: _____

Protocol: _____ Tentative Transplant Dates: _____
 _____ Stem Cell Source: Marrow PB Cord

HLA Matching: Sib 6/6 5/6 Haplo Haplo Sib MUD

ORGAN EVALUATIONS & DIAGNOSTIC TESTING				
Diagnostic Studies	Needed	Date Completed	Reviewed	Comments
CT Sinus w/o contrast				
CT Chest w/o contrast				
CT Abd with contrast				
MRI Brain w/o contrast				
Echocardiogram				
EKG				
Pulmonary Function Tests				
Pulse Ox	_____		_____	
Nuclear GFR	_____		_____	
Other:	_____		_____	
Laboratory Testing	Needed	Date Completed	Reviewed	Comments
BMT Serologies	_____		_____	
CMV IgG/IgM				

EBV IgG/IgM	_____		_____	
HSV IgG/IgM	_____		_____	
Toxo IgG/IgM	_____		_____	
Varicella IgG	_____		_____	
IgG, IgM, IgA				
ABO/Rh				
HLA Confirmatory	_____		_____	Initial Typing Sent:
Anti- HLA Ab Screen	_____		_____	
Lymph Subsets Panel 1	_____		_____	
Cystatin C	_____		_____	
CBC, CMP, Mg, Phos, PT/PTT, TSH, free T4, Ferritin, Direct Bili				
RFLP				
Pre-BMT Chimerism				
Urinalysis				
Procedures	Needed	Date Completed	Reviewed	Comments
Bone Marrow Aspirate/Biopsy				
Lumbar Puncture				
DL CVL Placement				
PAC removal				
Fertility Preservation				

G tube Placement				
Other	Needed	Date Completed	Reviewed	Comments
Advanced Care Planning				
Consults	Needed	Date Completed	Reviewed	Comments
Cardiology				
Child Life				
Dentistry				
Endocrinology				
Fertility	_____ .		_____	
Infectious Disease				
Neurocognitive				
Neurology				
Nutrition	_____ .		_____	
PANDA	_____ .		_____	
PICU				
POCC				
Pulmonary				
Psychology				
Renal				
Social Work				

Transfusion Medicine				
Radiation	_____ Needed	Date Completed	_____ Reviewed	Comments
Consult Request	_____ _____		_____ _____	
Simulation				
Transport	_____		_____	
Radiation Orders	_____ _____		_____ _____	
Prior to Admit	Needed		Completed	
Treatment Consent				
Infusion Consent				
Blood Product Transfusion Consent				
Stem Cell Product Rx				
OR Time for Harvest				
Busulfan Kinetics				
Admit Orders				
History and Physical				
Roadmap Pharmacy Review				
Admission Calendar				
Pre-BMT Nursing Education				

Pre-BMT APP Education				
Comorbidity Form 14M				
Race/Ethnicity Form 14L				
Insurance Authorization				
Test (7days prior to admission)	Needed	Date Completed	Reviewed	Comments
Adeno PCR, Blood			.	
Adeno PCR, Urine			..	
Respiratory Viral PCR				
Pregnancy Test			.	

Appendix D
ACP Training Session Lesson Plan

Learning Objectives	Content Outline	Method of Instruction	Time Spent	Method of Evaluation
<p>Participant will verbalize:</p> <ul style="list-style-type: none"> • patients who are eligible for ACP • responsibilities of each team member in the ACP process correct ACP document to use (Voicing My CHOICES™) • where to locate the completed document 	<p>Eligible patients</p> <ul style="list-style-type: none"> • >15 years old • allogeneic HSCT • English speaking • No developmental or cognitive delays <p>Responsibilities of each team member during the new process (BMT schedulers, SW, MD/NPs, RNs)</p> <p>Completed documents</p> <ul style="list-style-type: none"> • Uploaded to BMT share drive • Copy in patient’s medical chart on admission 	<p>PowerPoint, educational handouts</p>	<p>15 minutes</p>	<p>Post-training survey</p>
<p>Increase knowledge of ACP</p> <p>Increase comfort with ACP discussions</p> <p>Increase comfort with using Voicing My CHOICES™ during ACP conversation</p>	<p>Instruction will be provided by the palliative care NP</p> <p>Introduction to ACP</p> <ul style="list-style-type: none"> • definition, purpose, evidence supporting its use in AYA patients, differences between ACP and ADs <p>Description of Voicing My CHOICES™</p> <ul style="list-style-type: none"> • review of the document • not legally binding • can and should be updated throughout treatment <p>Simulated ACP conversation</p>	<p>Educational handouts, including a copy of Voicing My CHOICES™</p> <p>Verbal instructions, simulated ACP conversations</p>	<p>45 minutes</p>	<p>Post-training survey</p>

Appendix E
Pre-Training Survey

1. What is your clinician role at CNMC?
 - a. Attending physician
 - b. Advance Practice Provider
 - c. Registered Nurse
 - d. Social Worker
 - e. Psychologist

2. How many years have you practiced your discipline?
 - a. < 5 years
 - b. 6-10 years
 - c. 11-20 years
 - d. > 20 years

3. How much training have you had in facilitating advance care planning with patients and their families?
 - a. None
 - b. A little
 - c. Some
 - d. A lot
 - e. More than enough

4. During the past 3 years, how many patients have you cared for who have died? (estimate)
 - a. 0
 - b. < 5
 - c. 6-10
 - d. 10-20
 - e. > 20

5. During the past 3 years, how many times have you regretted not having a discussion with a patient about advance care planning?
 - a. 0
 - b. < 5
 - c. 6-10
 - d. 10-20
 - e. > 20

6. In your opinion, when is the best time to bring up end-of-life decisions?
 - a. Before getting sick, while healthy
 - b. When first diagnosed with a life-threatening illness
 - c. When first sick from a life-threatening illness
 - d. When first hospitalized with a life-threatening illness
 - e. If dying

- f. Never
- g. All of the above
- h. Don't know
- i. Other (please specify)

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Advance care planning is:					
Useful	1	2	3	4	5
Necessary	1	2	3	4	5
Stressful	1	2	3	4	5
Uncomfortable	1	2	3	4	5
I am familiar with the advance care planning guide Voicing My Choices					
I feel comfortable discussing advance care planning with my patients	1	2	3	4	5
I wish I had more training on advance care planning	1	2	3	4	5

Appendix F
Post-Training Survey

1. Was the training provided helpful to you?
 - a. Very much
 - b. Somewhat
 - c. Undecided
 - d. Not really
 - e. Not at all

2. In your opinion, when is the best time to bring up end-of-life decisions?
 - a. Before getting sick, while healthy
 - b. When first diagnosed with a life-threatening illness
 - c. When first sick from a life-threatening illness
 - d. When first hospitalized with a life-threatening illness
 - e. If dying
 - f. Never
 - g. All of the above
 - h. Don't know
 - i. Other (please specify)

3. Who do you think is/are the best person/people on the treatment team to bring up end-of-life decisions with a patient? Select all that apply.
 - a. Physician
 - b. Advance Practice Provider
 - c. Registered Nurse
 - d. Social Worker
 - e. Psychologist
 - f. Child Life Specialist
 - g. Case Manager
 - h. Chaplain
 - i. Other (please specify)

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
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Advance care planning is:

Useful	1	2	3	4	5
Necessary	1	2	3	4	5
Stressful	1	2	3	4	5
Uncomfortable	1	2	3	4	5

I am familiar with the advance care planning guide Voicing My Choices	1	2	3	4	5
I feel comfortable discussing advance care planning with my patients	1	2	3	4	5
I wish I had more training on advance care planning	1	2	3	4	5
Voicing My Choices is:					
Helpful	1	2	3	4	5
Easy to Understand	1	2	3	4	5
Easy to use in leading an advance care planning discussion	1	2	3	4	5
Appropriate for this patient population	1	2	3	4	5

Appendix G
Final SOP

Advance Care Planning for Adolescent and Young Adult BMT Patients

1. PRINCIPLE

Adolescent and young adult (AYA) patients who undergo hematopoietic stem cell transplants (HSCT) are at high risk to develop life-threatening medical complications and substantial treatment-related morbidity. Despite their critically-ill status, the unpredictability of serious complications, and the possibility that immediate medical decision will need to be made on their behalf, advance care planning is not routinely performed with AYA patients. The lack of advance care planning (ACP) discussions or documentation can lead to incongruence between AYA patients and caregivers about end-of-life (EOL) preferences, poor communication between patients and providers, and unwanted medical interventions. Early initiation of advance care planning has been shown to be safe and feasible for AYA patients facing life-threatening illnesses.

2. PURPOSE

The purpose of this SOP is to implement a standardized procedure for the initiation of advance care planning discussions and completion of advance care planning documentation for AYA patients ages 15 years and older who are undergoing HSCT. This SOP provides instructions for the identification of patients who are eligible for ACP, the scheduling and documentation of ACP discussions, and the maintenance of ACP documents.

3. POLICIES

All patients 15 years and older will be invited to participate in ACP, including discussion of EOL care decisions and communicating their preferences via the ACP) guide, Voicing My CHOICES™, according to the procedures detailed in Section 9.

Personnel

The pre-transplant ACP meetings will be conducted by the primary APP for the patient. The primary APP may delegate this responsibility to a member of the healthcare team who has an established and trusted relationship with the patient, including the primary MD, the BMT social worker, PANDA, and the psychosocial team. After the patient is admitted to BMT, members of healthcare team may continue to hold follow up ACP discussions as necessary.

4. SPECIMEN

Not applicable.

5. MATERIALS

Voicing My CHOICES™ (available from the non-profit organization Aging With Dignity)

6. SAFETY

All operations performed under this SOP will be executed according to Children's National's policies on patient safety and confidentiality. Patient participation in ACP is completely

voluntary. Psychosocial support is available for patients and families who experience distress during or after the advance care planning meetings.

7. RECORDS/FORMS/DOCUMENTS

See Section 5 “Materials”

8. QUALITY CONTROL

The advance care planning meeting should be marked on the stem cell transplant checklist and the discussions should be documented in the medical record.

9. PROCEDURE

Section 9.1: Identification of Eligible Patients

All patients who meet the following criteria will be identified as eligible for ACP planning consultation.

- Age 15 years or older
- Developmentally appropriate, as assessed by the medical team
- Candidate for Allogeneic HSCT or Autologous HSCT (excluding stem cell rescues)

Section 9.2: Scheduling of Pre-Transplant ACP Consultation

The primary APP for the patient will identify eligibility at the time the stem cell checklist is completed by primary transplant attending (usually 6-8 weeks prior to planned admission). Primary APP/MD team will ensure “ACP Planning” is checked on the stem cell checklist prior to the pre-BMT workup scheduling by program associate.

For eligible patients, an additional 30 minutes will be added to “APP Education/Consult” during the pre-BMT workup as allowed for introduction of the ACP document. As an alternative, a separate 30 minutes can be scheduled on a different day if needed to facilitate other consultations and/or organ evaluation. At the pre-transplant lab visit the week prior to admission, these patients will have an automatic escalation to 1 hour pre-transplant office evaluation to facilitate further discussions and/or completion of the first page of Voicing My CHOICES™ prior to admission.

Section 9.2: Management of Advance Care Planning document

Patients may finish as much of the document as they prefer, but it is suggested that, at minimum, the “My Signature” and “My Medical Care Decisions” pages are completed. Upon completion of the document, the durable copy will be copied for the BMT team with the durable document given to the patient. A copy will be scanned in to the department I-Drive under the patient-specific folder by the BMT Social Worker. The primary APP/MD and/or social worker will keep a paper copy to be put in to the medical chart on admission. The ACP discussion and Voicing My CHOICES™ document participation will be documented in the electronic health record as a BMT Clinic Event note titled pre-BMT Advance Care Planning.

At day +30, if the patient is still admitted without expected discharge within one week, the inpatient APP will prompt a discussion (or delegate to PANDA, Social Work, or Psychology) for re-evaluation of the ACP document with the primary team and/or

appropriate personnel and consider updating the document. For prolonged admissions or unexpected changes in care, the medical team should consider further discussions with the patient regarding advanced care planning decisions.

10. INTERPRETATION

See Section 9 “Procedure”

11. RESULTS REPORTING

The completed Voicing My CHOICES™ document will be stored in the patient’s medical chart and stored on the BMT share drive. The ACP discussion will be documented in the electronic health record as a BMT Clinic Event note titled pre-BMT Advance Care Planning.

12. LIMITATIONS

Patients and/or caregivers may not want to participate in advance care planning. Participation in these discussions, while encouraged, is completely voluntary.

13. ATTACHMENTS

Stem Cell Transplant Checklist

Voicing My CHOICES™

Appendix H
Weekly Audit Tool

Patient Code	Voicing My CHOICES™ Completed	EHR Documentation of ACP Discussion	Voicing My CHOICES™ hard copy located in patient's chart	Voicing My CHOICES™ uploaded to BMT shared access drive	Voicing My CHOICES™ easily located at patient discharge

0 = No
1 = Yes