

Family Centered Advance Care Planning for Teens Living with Cancer (FACE-TC)

Training Manual for FACE-TC Intervention



Acknowledgements

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Introduction

What is advance care planning?

Advance care planning is a process of planning for future medical care so the patient has a voice in treatment choices in the event the patient is unable to make decisions. This dynamic process involves exploration of the patient's understanding of their illness, fears and experiences, reflections on their goals and values for their future medical care, and discussion of future treatment preferences. This process of collaborative communication builds a sense of trust between the patient, the physician/healthcare providers and their families.

What is this manual?

This manual is a companion to the FACE-TC Intervention materials. It contains a structured outline for each of the three (3) FACE-TC sessions; and resources which can be used to help others explore and learn a model of navigating advance care planning (ACP) conversations with adolescents living with a life-threatening illness.

The manual is intended as a guide and selected materials can be adapted to a variety of situations and clinical applications. It includes ideas and suggestions for training and communication strategies. Contact information is provided on consultation and education services on the Respecting Choices Next Steps ACP program implementation in your healthcare organization. You may already be an experienced ACP facilitator and can use that experience and skill, bringing in your own stories and case studies.

Who is it for?

It is written for those with some experience in palliative care or managing patients with advanced illness who want specific strategies to support training for pediatric advance care planning (pACP). Qualified professionals for pACP skills training will usually be experienced health professionals (palliative care providers, nurses, social workers) but the materials can also be used by those in allied professions, or training such as graduate students in psychology, nursing, or public health.

Program Overview: What is FACE-TC?

Family Centered Advance Care Planning (FACE) Teens Living with Cancer (TC)

FACE-TC is a comprehensive advance care planning (ACP) program adapted from the Respecting Choices model for adults with advanced illness.

The purpose of the FACE- TC intervention program is to facilitate conversations about future healthcare decisions, including end-of-life (EOL) care between adolescents living with cancer (or other life-limiting illnesses) and their legal guardians or surrogates. Specific goals of the FACE-TC program are to train qualified professionals to competently deliver a standardized intervention, thereby opening channels of communication that result in increased congruence in treatment preferences, decrease decisional conflict. This process supports the completion of an advance directive, the teen and their family's psychological adjustment, and improved quality of life.

The FACE-TC intervention program consists of three 60 to 90-minute sessions in a face-to-face format with a trained/certified interviewer:

1. Lyon Family Centered Advance Care Planning (ACP) Survey© - Adolescent and Surrogate versions. This survey is used as a tool to engage participants in advance care planning and end-of-life (EOL) decision-making. .
2. Respecting Choices Next Steps (NS) ACP Interview (Briggs and Hammes). This patient-centered, structured interview is used to explore the patient's (and legal guardian's) representation of the patient's illness; open channels of communication between the dyad, and discuss goals of care in "bad outcome" situations. One end-product of this conversation is the creation of a "disease-specific" advance directive.
3. The Five Wishes© advance directive document. This session is used to assist the patient in completing one type of advance directive that reflects the patient's goals and values

To ensure protocol fidelity and patient safety during the FACE-TC study at Children's National, each session was immediately followed by 15 to 30 minute assessment questionnaires. The adolescent and their legal guardian/surrogate completed the Quality of Facilitator Communication and Satisfaction questionnaires with a person other than the trained/certified interviewer. Using these process measures to assess participants' ratings of the sessions will

allow your program to evaluate the quality of the discussions with the trained facilitator; these measures will also allow for quality assessment of your program.

Resources Needed

Facilitator Training

- ✓ Respecting Choices® NS ACP Facilitator Certification: A disease-specific program.

FACE-TC Intervention Materials (by Session)

Session 1 Materials:

- ✓ The Lyon Family Centered Advance Care Planning Survey
 - Adolescent and Surrogate versions
- ✓ The Quality of Patient-Interviewer Communication questionnaire
- ✓ Session Satisfaction questionnaire

Session 2 Materials:

- ✓ Respecting Choices NS ACP (Disease-Specific) Interview Tool*
- ✓ Respecting Choices Statement of Treatment Preference/Life-Limiting Cancer for Adolescents*
- ✓ The Quality of Patient-Interviewer Communication questionnaire
- ✓ Session Satisfaction questionnaire

***These materials are provided in conjunction with the Respecting Choices NS ACP Facilitator Certification Program. All Respecting Choices® materials are created and distributed by Gunderson Health System in La Crosse, WI. The Respecting Choices® ACP Facilitator tools and other curriculum (online) can be purchased at:**

<http://www.gundersenhealth.org/respecting-choices/training-and-certification/online-courses/facilitator-curriculum>

Session 3 Materials:

- ✓ Five Wishes© Advance Directive document
- ✓ The Quality of Patient-Interviewer Communication questionnaire
- ✓ Session Satisfaction questionnaire

Respecting Choices Next Steps Advance Care Planning: “A Disease-Specific Advance Care Planning Program”

Respecting Choices® (www.respectingchoices.org) is an internationally recognized, evidence-based ACP program based in the U.S. and provides ACP consultation nationally and internationally.

Known as leaders in the field, Respecting Choices offers a systematic approach to building an effective advance care planning (ACP) program, resulting in successful implementations for healthcare organizations and communities around the world.

Benefits of the Next Steps ACP Program for Your Healthcare System

- Implementation of an evidence-based ACP program for high risk patients with chronic, progressive illness to complement your existing disease management and palliative care initiatives
- Documentation of specific patient goals for life-sustaining treatment in advance of a medical crisis
- Strengthened healthcare agent’s role as an effective substitute decision maker by increased understanding of his/her loved one’s goals for future medical care
- Greater patient and family satisfaction from patient-centered communication and end-of-life decision making
- Focused/concentrated use of resources at end of life due to patient directed care plan (e.g., patient chosen interventions)
- Increased use of comfort care services (e.g., palliative care consults, hospice referrals, hospice length of stay)

Lessons we have learned:

- *Leadership is critical.* It is important to have leaders who understand the short and long-term goals of a comprehensive ACP program. Leaders must be identified at multiple levels: administration, steering committee, project coordination, pilot areas, health professionals (physicians, nurses, social workers), and other communities as necessary.
- *Administrative support is essential.* The time and resources needed to implement a successful advance care planning program must be recognized and supported by

administrative representatives at multiple levels. Mechanisms to keep administration involved and supportive must be developed.

- *Systems must be created or improved to honor written advance care plans.* There are many practices that must be revised or developed to ensure individuals' preferences are honored. One of the key systems that must be improved is the consistent entry, retrieval, update, and transfer of advance care plans that have been created. Trained facilitators can improve the quality of ACP discussions and create written plans that reflect an individual's preferences for future medical care. However, there are no guarantees that these preferences will be honored if community-wide systems are not created.
- *Quality improvement activities are important to motivate and engage others.* Many teams miss opportunities to demonstrate success when organized efforts to collect baseline data and measure outcomes specific to identified goals are not conducted.

The Respecting Choices Next Steps ACP program provides consultation to assist in addressing the lessons for successful implementation, and a competency-based Next Steps facilitator certification training program.

A key component of the FACE-TC intervention is the use of trained/certified facilitators during the Respecting Choices NS-ACP interview (session 2). ***The Respecting Choices NS-ACP Facilitator Certification Program*** identifies and reinforces a set of skills to help engage patients with advanced and/or life-limiting illness, and their families, to make timely and informed healthcare decisions specific to the complications they are likely to face in the future. This 2-day program includes the following components:

- Online ACP course
- NS ACP Facilitator Manual
- 2-day skills based classroom certification
- Respecting Choices® NS Interview tools and related materials
- Facilitator Certification Competency Criteria Checklist
- Video Demonstrations of all stages of the NS interview, including two pediatric interview segments: (1) Stage 2 of Respecting Choices® interview; (2) Stage 4 of Respecting Choices® interview

Facilitators are certified through the *Respecting Choices*® NS ACP competency criteria based on a submitted video demonstrating fidelity in implementing Session 2 - the Respecting Choices NS® Family Centered-Cancer Specific ACP Interview.

Facilitator Training Procedure

Respecting Choices Faculty (including Linda Briggs, MS, MA, RN) and Maureen Lyon, PhD, are available to assist healthcare organizations to implement the Respecting Choices Next Steps ACP Program for Adolescents living with Life-limiting illness. This program involves both consultation and education.

Training Tools/Instruments

All Respecting Choices® materials are created and distributed by Gunderson Health System in La Crosse, WI. The Respecting Choices® ACP Facilitator Curriculum (online) can be purchased at <http://www.gundersenhealth.org/respecting-choices/training-and-certification/online-courses/facilitator-curriculum>. Descriptions of each Respecting Choices® tool used in the FACE-TC Intervention can be found in appendix A.

To arrange Respecting Choices® consultation and education on the Next Steps ACP Facilitator Program for Adolescents with Life limiting illness, please contact:

Bereavement and Advance Care Planning Services

ATTN: Britt Welnetz, Business Development Representative, Respecting Choices

1900 South Avenue, MS AVS-003

La Crosse, WI 54601

blwelnetz@gundersenhealth.org

Session 1: Lyon Family Centered Advance Care Planning (ACP) Survey

Aim of the Session

- (1) To determine if and when the adolescent wants to be involved in decision making about EOL care;
- (2) To identify values, beliefs and life experiences with illness.

Length of Time for Session

- 30 – 45 minutes Adolescent Survey
- 30 – 45 minutes Surrogate Survey

* Total time if administered by one facilitator is 60-90 minutes; If two (2) facilitators are available, these survey administration can be completed concurrently.

Introduction

The Lyon Family Centered Advance Care Planning Survey was originally developed by including elements from an approved adaptation of the AARP survey about factors influencing EOL decision-making. In 2002, the AARP conducted a mail survey of AARP members age 50 and older in North Carolina. From a random sample of 8,000 members selected from their database.

Specifically, the Lyon Family Centered Advance Care Planning Survey is a three part, 31 question survey designed to (1) assess the adolescents' and surrogates' values, beliefs, and life experiences with illness and EOL care; and (2) assess when adolescents and their surrogates prefer to initiate EOL discussion and planning.

The Lyon Family Centered Advance Care Planning Survey (adolescent and surrogate versions) also includes items from the earlier version of the Lyon adolescent survey examining adolescent wishes to participate in shared decision making and if so, when. This survey engages the participant in EOL questions referring to general illness and not one specific illness.

This session prepares or 'primes' the adolescent and their surrogate/legal guardian for the next session in which they will participate in a specific discussion exploring the adolescents' illness and their wishes for medical treatment in the event they cannot speak for themselves.

See Appendix C for Adolescent and Surrogate/legal guardian versions of the survey.

Session 1 Procedure

The certified facilitator/interviewer who administers the survey and marks the subject's responses conducts this session in a structured interview format.

- 1) Interviewer will orient the dyad to the study and to the issues, providing information, such as the right to change your mind or to change surrogates, the right of patients who decide to forgo life-sustaining treatments to be offered other important treatments and to not be abandoned.
- 2) The adolescent will then be surveyed separately from the guardian or surrogate in a private room, following the recommendations of the ATN focus group and the recommendations made by experts in the field (McCabe MA, Rushton CH, Glover J, et al. 1996). Implications of the Patient Self-Determination Act: Guidelines for involving adolescent in medial decision making. *Journal of Adolescent Health*, 19,319-324.)
- 3) The guardian/surrogate will be surveyed privately with parallel questions with regard to what their adolescent is thinking and attitudes about EOL care. This provides an opportunity to identify areas of congruence or agreement between the adolescent and their surrogate prior to Session 2, the Respecting Choices interview.

Session 2: Respecting Choices NS ACP® Interview

Aim of the Session

- (1) To facilitate ACP conversations and shared decision making between the adolescent and guardian/surrogate with a trained/certified interviewer, providing an opportunity to express fears, values, beliefs and goals regarding future medical treatments ;
- (2) To prepare the guardian/surrogate to be able to fully represent the adolescent's wishes.

Length of Time for Session

- 60-90 minutes

Introduction

The Respecting Choices NS ACP interview has been successfully tested in randomized controlled trials and clinical implementation. This patient-centered interview technique creates a shared decision making process, opening communication pathways, and building and strengthening relationships

The Respecting Choices Next Steps (disease-specific) Facilitator Certification Program® used a competency based approach that identifies and reinforces a set of skills to help engage patients with advanced and/or life-limiting illness, and their families, to make timely and informed healthcare decisions specific to the complications they are likely to face in the future.

During the session with the adolescent and their legal guardian/chosen surrogate, the interviewer will orient the patient and family to the session explaining that the goal of the ACP conversation is to promote individual choice and understanding, and allow the **adolescent a voice** in their medical care if a complication from the illness occurs and the adolescent is unable to speak for themselves. The interviewer will also explain that the interview is an opportunity for the adolescent to express his or her wishes.

See Appendix A for further descriptions of the key components used in the Respecting Choices NS ACP interview.

Session 2 Procedure

The trained Next Steps (disease-specific) ACP interviewer will facilitate the structured and individualized NS interview with the patient and family in an outpatient or inpatient (non-ICU) setting. The structured interview includes five (5) stages to assess the patient and the patient's family's understanding of the adolescent's illness as well as provide an outline of communication techniques for the facilitator.

Stage 1 assesses the adolescent's understanding of his or her current medical condition, prognosis, and potential complications, as well as his or her fears, concerns, hopes, and experiences. The adolescent and guardian/surrogate do not have to acknowledge the stage of illness.

Stage 2 explores experiences the adolescent might have regarding planning for future medical decision-making. This exploration assists in defining goals and value and promotes mutual understanding

Stage 3 briefly reviews the rationale for future medical decisions the adolescent would want the legal guardian or chosen surrogate to understand and act on. The facilitator explains the purpose of advance care planning.

Stage 4 uses the Statement of Treatment Preference tool to describe real clinical situations commonly expected with life limiting cancer that the adolescent could experience and related treatment choices that the surrogate might need to make. The adolescent is encouraged to express his/her goals of care in selected "bad outcome" situations. The adolescent's understanding of the benefits and burdens of different choices are explored. The interview is also intended to insure the guardian/surrogate understands the adolescents concerns and perspectives through such questions as "Do you understand what he/she wants?" and "Can you honor your loved ones decisions?". The Statement of Treatment Preference tool can be completed with the adolescent during this session and entered into the medical record as an addendum to the advance directive (e.g., Five Wishes)

Stage 5 summarizes the value of the previous discussion for patient and guardian/surrogate, as well as the need for future discussions as situations and preferences change. Any remaining questions or gaps in information regarding health condition or care and treatment options are identified and the dyad is referred to the physician or other appropriate resources as needed.

Tool/Instrument Information

The Respecting Choices NS ACP (Disease-Specific) Interview Tool cannot be purchased separately from the Respecting Choices Next Steps program. For more information, you can contact:

Bereavement and Advance Care Planning Services
ATTN: Britt Welnetz, Business Representative, Respecting Choices
1900 South Avenue, MS AVS-003
La Crosse, WI 54601
blwelnetz@gundersenhealth.org

Session 3: The Five Wishes©

Aim of the Session

- (1) To identify which person the teen wants to make healthcare decisions for him/her
- (2) To identify the kind of medical treatment the teen wants
- (3) How comfortable the teen wants to be
- (4) How the teen wants people to treat him/her

Length of Time for Session

- 30 – 60 minutes

Introduction

Five Wishes© is a legally binding advance directive that helps a person express how they want to be treated if they are seriously ill or unable to speak for him or herself. It is a living will that explores the patient's personal, emotional and spiritual needs as well as the patient's medical wishes. It was written with the help of the American Bar Association's Commission on the Legal Problems of the Elderly and was created by Jim Towey, the founder of Aging with Dignity.

Five Wishes© is legally sufficient for a person over the age of 18 in most states in the United States. It can be used as a tool to help adolescents under 18 to participate in shared decision-making, discussing their preferences for their own end-of-life care with their family. Wiener and colleagues (2008) found the Five Wishes© to help teens with cancer and developmentally appropriate. They also observed that no youth experienced talking about the issues in the Five Wishes© as "stressful" or "very stressful." For adolescents under the age of 18 the Five Wishes© must be signed by their parent or legal guardian to be legally sufficient.

Session 3 Procedure

In Session 3, processes, such as labeling feelings and concerns, as well as finding solutions to any identified problem, are facilitated. Appropriate referrals are made to help resolve disagreements over decision-making (e.g. a hospital ethicist, Chaplain, or mental health professional). The Five Wishes© advance directive document is just one of the many living wills

available to the public; others may be used to assist in the documentation of the adolescent's goals, values, and preferences for future medical treatment.

- Five Wishes© is administered to the adolescent during Session 3 of the intervention. The adolescent should complete this along with their parent/proxy. Adolescents and guardians should be encouraged to let their primary healthcare provider (HCP) know their treatment preferences.
- For adolescents under the age of 18, the Five Wishes© must be signed by their legal guardian.
- If the Five Wishes© is signed and witnessed, it should be placed in the patient's chart and the primary HCP should be notified in person that it is in the medical chart and given a copy.
- Standard procedures for advanced directives in your organization should be followed. Families should be thanked again for their participation. Participants should be encouraged to speak with their oncologist or primary healthcare providers if they have any questions or concerns.

Tool/Instrument Information

You can visit the Five Wishes© page to obtain hard copies of Five Wishes© to be delivered. For facilitator training purposes, web links to segments of the Five Wishes© video are found here without charge:

Five Wishes Introduction: <http://youtu.be/oEOevM-wass>

Wish 1: <http://youtu.be/RMeeGwWzHzs>

Wish 2: http://youtu.be/Q2otAYH_A5E

Wish 3: <http://youtu.be/N7pMvEgXvvo>

Wish 4: http://youtu.be/42_w6iSF_sk

Wish 5: <http://youtu.be/wHWl3lN5qZo>

Signing: <http://youtu.be/43kXWZWJrHA>

Commonly Asked Questions

What if I live in a state that's not a Five Wishes© state?

Note: Although we used the Five Wishes© as the advance directive for FACE-TC, we did this because it was the document approved by our hospital and legal in Washington, DC.

Other programs, or health care organizations may prefer to use a different advance directive document that conforms to state statute and/or community preference.

Although this is the evidence-based advance directive the FACE-TC study at Children's National Health System used, we do not want to make use of the Five Wishes© a demand or FACE-TC program requirement.

What if I live outside of the US?

Although a Five Wishes© may not be a legal document outside of US, Five Wishes© is a good way to express your wishes to family and doctor.

What happens if I move to another state?

If you move to a Five Wishes© state, it is still valid. If you move to a state that does not recognize Five Wishes© as a legal document, then complete your new states' advance directive form and attach your Five Wishes©.

Can I change my Five Wishes© or other appropriate Advance Directive?

Yes, feel free to update it and often as you'd like. On the document is that are no longer valid. Write "revoke" on it and destroy the old copy.

Can I make copies of Five Wishes© or other appropriate Advance Directive?

Yes, you can make copies of your completed form. Please do not make copies of blank copies of the Five Wishes© (or your advance directive) form.

Quality Assurance Assessments

Purpose

Using an evidence-based, structured conversation and incorporating facilitator interpersonal training is a way to improve communication about EOL with pediatric patients. To ensure protocol fidelity and patient safety as well as appropriately assess communication during the FACE-TC Intervention pilot, each session was immediately followed by 10 to 15 minute assessment questionnaires.

The adolescent and their legal guardian/surrogate completed the Quality of Facilitator Communication and Satisfaction questionnaires with a separate FACE team member, designated as the “assessor,” to administer post-session questionnaires. These assessments take place with the participant and his/her designated surrogate in separate rooms to maintain confidentiality of responses.

These particular process measures assessing participants’ ratings of the sessions will allow your organization to evaluate the **quality** of the ACP discussions with the trained facilitator; these measures will also allow for quality assessment of your ACP program.

Quality of Patient-Interviewer Communication Questionnaire

The Quality of Patient-Interviewer Communication (*Curtis et al.*) form was designed to evaluate the discussion the participant had with the trained facilitator. The questionnaire asks the participant to consider how he/she felt about the communication between his/herself and the facilitator during the session. The first four questions examine the quality of communication specifically with the trained ACP facilitator. The final question explores the quality of the overall discussion during the session.

An example of this form can be found in Appendix D.

Satisfaction Questionnaire

The Satisfaction Questionnaire, developed for the FACE-TC study, consists of 13 questions on a five point Likert scale with responses from “strongly disagree” to “strongly agree.” The final question on the form asks the participant if there was anything else they want to share about how he/she felt during the session.

An example of this form can be found in Appendix D.

Post-Intervention Communication with Physician

In the Children's National FACE-TC study, it was protocol for the trained interventionists to email (secured) the adolescent's completed Statement of Treatment Preferences and a copy of the completed Five Wishes© document, along with electronic correspondence (i.e. secured email) outlining the participants' experience, to the treating physician, for example noting if the family had specific questions or if there was disagreement about treatment preferences.

The *Statement of Treatment Preferences* and **completed** advance directive document, such as the Five Wishes©, are scanned into the electronic medical record. A copy is given to the family.

It is recommended that your organization choose a similar procedure to communicate with the adolescents' treating physician, adapting it to your institution's policies and procedures.

Protection Against Risks

In the FACE-TC study at Children's National, Dr. Lyon was primarily responsible for protection against risks. However, protection against risks is the responsibility of all members of an ACP-Facilitation team.

The pediatric oncology patient sample is treatment and disease experienced. Many have participated in research studies throughout their life. They are quick to know if they want to do a study or not. Adolescents with cancer who are seriously ill and/or are at the end of life may be at greater risk of emotional distress. In conferring with the consultant for the FACE-TC pilot study at Children's National, Pamela Hinds, PhD, RN, FAAN, who has conducted many studies with children dying of cancer, we recommend the following as overall guidelines:

1. "Commitment to no surprises"

- a. Hinds' research shows there is decreased likelihood of a feared distress reaction if patients and families know exactly what is going to be done during the study. First, the family will be shown the questionnaires, survey, Respecting Choices Interview, Questions, or Five Wishes©, appropriate study visit, and ask if it is o.k. to continue.
- b. Next we will show the survey etc. to the adolescent and ask the adolescent if he/she would like to continue.
- c. The facilitator will state, "You could be bothered by some of these questions. You have a right to say pass. You are in complete control and you can stop anytime you want."

2. **If something did upset a participant**, after supporting the family, the facilitator will ask if there is a staff person they feel really good about that they would like to meet with and we will contact that staff person to support the participant.

Statement of Intention

With the profound appreciation and reverence of research with this unique population, our plan is to integrate **bioethical principles** into the FAMily-CEntered Advance Care Planning for Teens with Cancer (FACE-TC) intervention:

- First, to **respect the autonomy** of adolescents, we plan to provide adolescents a structured setting in which to voice their wishes, in a way that protects everyone from feeling overwhelmed by fear or sadness.
- Second, to practice **beneficence**, we plan to provide a structure that enables adolescents and their families to have conversations about their attitudes, beliefs, experiences, and wishes with regard to future medical treatment, including end of life.
- Third, to practice **justice**, we intend to ensure that our research includes all ethnic and illness groups and that each group is treated with fairness and equality.
- Fourth, to integrate the principle of **nonmaleficence**, we are sensitive to the need to provide safeguards to prevent harm and to assess whether or not harm has occurred throughout the course of the study.
- Finally, we intend to implement this intervention with **fidelity**.

Program interventions like FACE-TC do more than simply document adolescents' wishes for future medical care treatment; we work to insure that the ACP process is meaningful for the adolescents and their families.

When asked about their experience during the FACE-TC sessions, adolescent's comments included: "I think it just refocused...my decisions." "It was a good session. I learned a lot about what to think about- good thought process." Comments from the families included: "I think this is very, very good and this is a way to bring up difficult topics to the table." "This was a relief...I always want to know what my son thinks." "The questions asked were important questions [I] had not thought about before and [I] can now discuss with [my] son."

Research Findings

Since the conclusion of the pilot study at Children's National Health System in June 2012, Dr. Maureen Lyon and colleagues have worked diligently to disseminate and publish the findings from the FACE-TC intervention. Listed below are two articles that have been accepted and published by the Journal of Adolescent Health (2014) and the Journal of the American Medical Association (2013). The articles explore the feasibility, acceptability and efficacy of FACE-TC.

Maureen E. Lyon, Shana Jacobs, Linda Briggs, Yao Iris Cheng, Jichuan Wang. **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 - 08 January 2014 (10.1016/j.jadohealth.2013.10.206)

<http://www.jahonline.org/article/PIIS1054139X1300743X/fulltext>

Abstract

Purpose: To test the feasibility, acceptability and safety of a pediatric advance care planning (pACP) intervention, Family Centered Advance Care Planning for Teens with Cancer (FACE-TC).

Methods: Adolescent (ages 14-20)/family dyads (N=30) who knew cancer diagnosis participated in a 2-armed randomized controlled trial. Exclusion criteria included severe depression, impaired mental status. Acceptability was measured by *Satisfaction Questionnaire*. General Estimating Equations (GEE) models assessed the impact of FACE-TC on 3-month post-intervention outcomes as measured by *Peds QL-Generic*; *Peds QL-Cancer Module*; *Beck Depression and Anxiety Inventories*; *Spiritual Well Being Scale of the Functional Assessment of Chronic Illness Therapy-IV*; and advance directive completion.

Results: Acceptability was demonstrated with enrollment of 72% of eligible families; 100% attendance at all 3 sessions; 93% retention at 3-month post-intervention; and 100% data completion. Intervention families rated FACE-TC worthwhile (100%), while adolescents' ratings increased over time (65%-82%). Adolescents' anxiety decreased significantly from baseline to 3 month post-intervention in both groups ($\beta=-5.6$, $p=0.0212$). Low depressive symptom scores and high quality of life scores were maintained by adolescents in both groups. Advance directives were located easily in medical records (100% FACE-TC adolescents vs. 0% controls). Oncologists received electronic copies. Total Spirituality scores ($\beta=8.1$, $p=0.0296$) were significantly higher among FACE-TC adolescents vs. controls. FACE-TC adolescents endorsed the best time to bring up end-of-life decisions: 19% before sick; 19% at diagnosis; 0% when first ill or hospitalized; 25% if dying; and 38% all of the above.

Conclusion: FACE-TC demonstrated feasibility and acceptability. Courageous adolescents willingly participated in highly-structured, in-depth pACP conversations safely.

Keywords: adolescent, advance care planning, advance directive, African-American, cancer, communication, decision-making, end-of-life, family intervention, pediatric palliative care, patient perspective, randomized controlled trial, spirituality.

Implications and Contribution: FACE-TC is the first randomized clinical trial of pACP involving adolescents with cancer. This structured model meets the World Health Organization, Institute Of Medicine, and American Academy of Pediatrics recommendations for early palliative care that involves the patient, surrogate decision-makers, and physicians, moving the field of pACP forward.

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Abstract

Objective: To test the efficacy of FAmily CEntered advance care planning

Patients/Participants: Adolescents aged 14-21 with cancer and their surrogates/families (N=60 participants).

Methods: Two-group, randomized controlled trial. Dyads (N=30) received three-60 minute sessions one week apart. Intervention dyads received: (1) Lyon Survey; (2) Respecting Choices Interview; and (3) Five Wishes. Controls received standard of care plus information.

Main Outcome Measures: Statement of Treatment Preferences, Decisional Conflict Scale.

Results: Adolescents' mean age was 16; 60% male; 50% White, 43% Black. Diagnoses were leukemia 47%, brain tumor 27%, solid tumor 20% and lymphoma 7%. Significantly increased congruence was observed for intervention dyads compared with controls for four of the six disease-specific scenarios, for example Situation 2, "treatment would extend my life by not more than 2-3 months," intervention dyads demonstrated higher congruence (Kappa= 0.660; $p=0.0002$) versus control dyads (Kappa= -0.0636; $p=0.6959$). P-value for testing equal Kappas is $p=0.0021$. Intervention adolescents (100%) wanted their families to do what is best at the time, while fewer control adolescents (62%) gave families this leeway. Intervention adolescents were significantly better informed about end-of-life decisions ($t=2.93$; effect size=0.961, 95% Confidence Interval=0.742, 1.180; $p < 0.013$, $p=0.013$). Intervention families were more likely to concur on limiting treatments than controls. Ethnic difference was found in only one situation.

Conclusions: Advance care planning enabled families to understand and honor their adolescents' wishes. Intervention dyads were more likely than controls to limit treatments. Underserved African-American families were willing to participate.