

Supplemental Information

SUPPLEMENTAL TABLE 5 FACE ACP Intervention

	Session 1	Session 2	Session 3
Session foundation	<i>Lyon Advance Care Planning (ACP) Survey - Adolescent and Surrogate Versions</i> to set stage for EOL conversation. 45 min average.	<i>Next Steps: Advance Care Planning Respecting Choices Interview Interview</i> (Briggs and Hammes, 2012–2013).	The <i>Five Wishes</i> is a legal document that helps a person express how they want to be treated if they are seriously ill and unable to speak for himself or herself. Unique among living will and health agent forms, it looks to all of a person's needs: medical, personal, emotional, and spiritual.
Session goals	To assess the adolescents' values, spiritual and other beliefs, and life experiences with illness and EOL care. To assess when to initiate ACP planning. To assess the family member's (surrogate decision-maker's) understanding of the adolescent's goals, values, spiritual and other beliefs, and life experiences with illness and EOL care.	To facilitate conversations and shared decision-making between the adolescent and surrogate about palliative care, providing an opportunity to express fears, values, spiritual and other beliefs, and goals with regard to death and dying. To prepare the guardian or surrogate to be able to fully represent the adolescent's wishes.	Which person the teenager wants to make health care decisions for him or her. The kind of medical treatment the teenager wants. How comfortable the teenager wants to be. How the teenager wants people to treat him or her. What teenager wants loved ones to know. Any spiritual or religious concerns teenager may have.
Session process	Orient family to study and issues. Adolescent is surveyed privately. Surrogate is surveyed privately with regard to what they believe their adolescent prefers.	Stage 1 assesses teenager's understanding of condition. Stage 2 explores teenager's philosophy about EOL decision-making. Stage 3 reviews rationale for future decisions teenager would want surrogate to act on. Stage 4 uses statement of treatment preferences to describe scenarios and/or choices. Stage 5 summarizes need for future conversations.	For adolescents under the age of 18, the <i>Five Wishes</i> must be signed by their legal guardian. Processes, such as labeling feelings and concerns, as well as finding solutions to any identified problem, are facilitated. Appropriate referrals are made. These sessions may include other family members or loved ones.

EOL, end of life.

SUPPLEMENTAL TABLE 6 Operational Definition of an Adverse Event by Using the Following Response Pattern on Satisfaction Questionnaire

Item	Question	Answer
5	It was too much to handle	Agree or strongly agree
7	It was harmful	Agree or strongly agree
1 ^a	It was useful	Disagree or strongly disagree
2 ^a	It was helpful	Disagree or strongly disagree
6 ^a	I felt satisfied	Disagree or strongly disagree
11 ^a	I felt courageous	Disagree or strongly disagree
13 ^a	It was worthwhile	Disagree or strongly disagree

For the purposes of this study, a serious adverse event will be defined as an emotional breakdown requiring hospitalization or inpatient behavioral health services for emotional distress very likely or certainly related to the study intervention.

^a In addition to answering agree or strongly agree to 1 of the first 2 questions, disagree or strongly disagree with all of the following.

SUPPLEMENTAL TABLE 7 Selected Linear Regression Model for Evaluating the Effect of Intervention on Family Member's Satisfaction Questionnaire Subscales (*N* = 111)

Parameter	Outcome			
	Positive Satisfaction Score		Emotional Reactions Score	
	Estimate (95% CI)	<i>P</i>	Estimate (95% CI)	<i>P</i>
Intervention group				
Control	—	—	—	—
FACE-TC	3.19 (1.74 to 4.63)	<.0001	-0.8 (-2.41 to 0.82)	.33
Surrogate age	-0.01 (-0.09 to 0.08)	.84	0 (-0.09 to 0.09)	.99
Surrogate sex				
Male	—	—	—	—
Female	1.07 (-0.85 to 2.98)	.27	0.23 (-1.95 to 2.42)	.83
Surrogate race				
Multiracial	—	—	—	—
White	-2.1 (-3.96 to -0.23)	.03	-0.34 (-2.4 to 1.73)	.75
Poverty				
No	—	—	—	—
Yes	0.06 (-1.58 to 1.7)	.94	0.94 (-0.87 to 2.75)	.30
On active treatment				
No	—	—	—	—
Yes	-0.86 (-2.64 to 0.91)	.34	-0.68 (-2.68 to 1.32)	.50

One missing outcome and 4 declined poverty data were excluded. —, the reference group for each parameter.

SUPPLEMENTAL TABLE 8 Qualitative Satisfaction Comments From Families in FACE-TC pACP in Response to the Query, “Is There Anything Else You Would Like to Tell Us About How You Felt During This Session?” (After Completion of Session 2, Respecting Choices Interview, During Which Time the AYA Completed the Statement of Treatment Preferences)

At the front end, when the study was first introduced, the topic of “end of life” was not made clear. This was okay for us since we are willing to participate but may have been difficult for some other families.

I felt like, for me, the order of the situations was reversed when presented: it went from best scenario to worst. When you start with the best, you're not even introduced to the worst, so you have no idea how much worse the situations are going to get. It's all relative: sort of like comparing different shades of green.

If questions were presented in a different order, my answers would have been different. (Surrogate did not wish to go back and change any of her answers and said she didn't want to revisit those thoughts and feelings again.) She went on to explain she thinks this was much more difficult because her daughter is healthy now, and it is hard to go back and think about scenarios like this.

It was evident how [patient] felt regarding her care, but she asked for clarification, which leads me to believe the questions should be asked in different ways to ensure understanding when it comes to kids.

After each of our times, we do end up talking about things (including with my wife): it brought up some good conversation. It's been good to hear what M thinks about some of these things.

During and after the session I felt prepared.

Everybody should talk about these topics, whether you are a teen or elderly or at any age.

I felt sad and it hurt talking about these situations, but it's better to be prepared than not. We never thought about these things before, but it's good to talk about them.

I hope this project has some benefit for other families because people need to know how to approach this subject. It helps parents to know what their teenager is thinking.

I think it's a good thing to do: once you get a little bit away from a life-threatening situation. Everyone should do this, ideally before you're in a situation where you have to. It's good to get it done.

I think it's something that needs to be talked about.

I think this has been valuable, especially for kids [patient's] age. Even though he's survived this for 6 years, we know it could come back and that he's at a higher risk of secondary cancers and other late effects. I really don't think these are things we would have ever talked about had we not been asked to participate [on this study].

I was concerned that my daughter might think her situation was worse than it was, but I still think it was very much needed.

I was really happy that we were able to do this and that it was something we really needed to do.

I'm glad we said yes to being in the study. Some things we “know,” but we don't really know for certain and aren't quite sure how to bring them up, so having someone to do that has been really nice.

I'm very open with patient, we talk about life, death good and bad, but, ultimately, when it comes down to it, I would never have spoken so in depth with him about this stuff. I have thought about it but would never have talked about it. He has said if he was in a vegetative state, he wouldn't want to live like that if he was incoherent.

If I had to sum it up in one word, I would say comfortable.

It brings up things we don't want to think about it, but it's good to talk these topics.

It has put in my mind that I have to talk to both of my children about my wishes so that they would know what I would want.

It made me feel like the entire family needs to sit down and talk about what all of us would like to have done in these situations. It would help alleviate some stress in the situations.

It opened my mind.

It was a good interview: people need to think about it, also shocked at my daughter's answers!

It was a good session: these are things that need to be discussed. We're happy that all of this is behind us now but still see definite value in doing this.

It was sad having to think about having to make those decisions for your child. But overall, the study's been good for L.

It's been good. We don't think R's cancer is going to come back, but, if it would, it's nice knowing we've had these hard conversations now and I know exactly what my daughter would want. Being part of this study just helped us bring it all out. It was so hard to talk about these kind of things when she had cancer, from the time she was first diagnosed, dealing with her cancer was just such a rush, and it was just hard to know when (and even if) to bring these kind of things up. Now I'm comforted knowing that we've had these really important discussions. The further out it gets from her cancer, the harder it is to even think about going back to those days. We were close before, but now we're really close: almost like being the same person; we really trust each other, and it's so good knowing exactly what she'd want if her cancer were ever to come back.

It's just good for everybody to get an understanding of what your child thinks because this is something you never talk about. It's just helpful to be able to discuss these things.

It's reality but it is scary. It is the reality, but it is scary, that's why I am going to talk again to him and influence him as I have told you. The mother is scared as I told you. I am going to talk with him and the family because it is scary. I am scared.

It's really hard as a mom because you would rather keep your kid alive and it's difficult when she has other thoughts. Some of her answers has me worried about how much this would “carry over” if stated on an advanced care directive and something were to happen not related to cancer. (Mom gave example of if daughter were in a motor vehicle accident and her ACD stated she would not want treatment if it meant she may not ever be able to walk or talk again: “would this mean they wouldn't even try to do surgery” (knowing that could be the outcome)?)

It's really hard, talking about it.

No.

No, just good to talk about this.

None.

Nope.

Not really.

Not really, except I do feel that it was helpful. It was food for thought for people.

Nothing.

SUPPLEMENTAL TABLE 8 Continued

Nothing. Question 6 was left blank as surrogate stated she did not know how to answer (because it created more questions for her to discuss with patient). Questions are too “cookie cutter, too open-ended (talking about cancer, but what kind of cancer? etc. Not all cancer is terminal); would change how questions are answered.”

Some questions: those were having me guessing about what patient would want were not helpful. What would be helpful to hear is his answers.

The scenarios really made me think about those situations and what she would really want. The last one made me think about whether I would honor her wishes or not.

Thinking about this makes me sad, but its good to talk about them so we know what he wants.

This was very helpful; we never considered discussing this before.

Tough questions regarding my child. Positive outlook makes it easier.

It was easy because we are so far removed, but 10 years ago those would have been harder and more emotional to answer.

My feelings were up and down regarding it. Sometimes I did feel courageous and strong, but other times when it would take me back to his treatment. I felt very scared. The first meeting was a lot of focus on religion and God and I didn't understand why we were being asked, especially other parents who might not be religious. Also, if my son was younger, I wouldn't want my teenager to make such hard decisions. And parents should be making their decisions. If he weren't old enough, I would be guiding him until he can make those decision and a 14yo can't make that kind of life deciding decision. Teens think they can do anything. Teens are fearless and parents should be wiser.

No.

No, it was something that should be discussed regardless of the age and was very helpful.

None.

Some scenarios were hard to think about, but important to think about these things even when it's hard.

Stuff we never really thought about before. We take things as they happen and never asked before what she wanted.

There are so many things to further discuss with my son and our family.

ACD, advance care document.

SUPPLEMENTAL TABLE 9 Qualitative Satisfaction Comments From Families in Treatment-as-Usual Group (Control Condition) in Response to the Query, “Is There Anything Else You Would Like to Tell Us About How You Felt During This Session?” (After Completion of Assessments at Study Visit 3)

I am glad we did not have to decide any of these questions during her leukemia.

A (patient initial) is now 3 years post: a lot of these things have already been “rolling around in heads” and part of conversations for a long time. I likely would have answered some of these questions differently 2 years ago when there were still a lot of unknowns. None of these are new questions.

I don't know that I got a benefit out of it. Did it create thought provoking thoughts? Yes, but beyond that, I'm still trying to find the worth in it.

I hope that the cancer does not come back.

I think it went well.

I think it's easier because my daughter is in remission. I don't how I would feel if she was still in treatment.

I think that these questionnaires could be brought up for any patient when they receive a diagnosis of cancer. I could see where a lot of people might answer yes to the “sad” or “hurtful” questions since it's not an easy thing to think about. A lot would depend upon the stage (of the patient's illness) you present this at. I hope that you get parents on board to visit this topic: it's not easy, but it is a way of opening up communication, especially when the parents may not be in agreement about what they would do and in those cases where the parents may not even be together.

It brought questions that we've never had to think about and some that we revisited.

It gave me closure and hope and understanding for everything we have gone through.

It is satisfying to help research the unknown and maybe help other parents and children who have to deal with this. I felt angry about cancer and its effects, not the questions asked.

It was interesting. I think it will open up dialogue.

It was something I don't normally think about, so I guess it was good for my soul.

It's not something that you normally think about, especially during treatment, you never think about the negative. That could be because of denial and because you want a positive outcome: there's always hope that some magical treatment may pop up (qualify for trial, etc.) both denial and hope are natural.

It's something we need to talk about.

No.

No.

No, intriguing, no nothing more.

Not at this time, nothing to add.

So glad we were asked to be a part of this process because it's kind of an awkward conversation to have. Even though he's not sick now, it gives us an opportunity to talk with him again: it's a different conversation now at age 14 than we would have had with him at age 10 when he was sick. It also gives him a chance to let us know what he's thinking about things.

These are questions we don't typically think about asking our kids, but we should. I don't think I would let her make all of these decisions, but it's really good to know what she is thinking which would help us in making our decisions. Sometimes I think we put too much pressure on our kids by expecting them to make all these kinds of decisions.

These are things that I never thought about before. Talking about these situations brought back all the difficult times we went through during diagnosis and treatment.

These questions would be easier to answer if I knew what my son wanted.

Thinks the whole thing is worthwhile, happy to participate surrogate's suggestion: keep in mind the timing of participating on study to diagnosis and treatment.

Patient has cancer very young and is well, so answers now would have been much different then

This allowed me to take a look at how god, family, and friends truly work to support us.

This is a good way to open lines of communication.

Very heavy questions to think about, but it's the reality.

When questions were being asked, “your brain goes back there”: it brought me back to the days when she was sick. As a parent, your natural instincts are to fight as hard as you can no matter what. I know that we will now be having some discussion about this, whereas, before now, we probably wouldn't have.

It was useful, platform to engage conversation and discuss the questions with my child.

Makes you think about things. Useful.

No.

No, just a reality check.
