

Understanding End of Life Decision Making in Teens with Cancer

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Abstract

Background and Significance of the Study Cancer is the leading disease-related death for adolescents.¹ Over 11,000 adolescents and young adults (AYA) die from cancer and other serious illnesses each year.² About 86% of AYAs want to participate in discussions related to EOL care.³ **Purpose** The culminating experience project is titled “Understanding End of Life Decision Making in Teens with Cancer” and presents the important public health topic of adolescent cancer that could lead to possible tragically young deaths. The purpose of this project is to examine patient-reported end-of-life values and needs of adolescents with cancer for ages 14-17 and ages 18+ in terms of differences in survey responses. **Methods** The advanced care planning cross-sectional survey was conducted between July 2016-April 2019 and included adolescents with cancer and their families recruited from 4 tertiary care pediatric hospitals. Analyzing specific survey items related to end-of-life decision making, knowledge, and important factors in death and dying between the younger adolescent group and older group, will help inform researchers, providers, care teams, families, and adolescent patients on how to best support patients and families when faced with the difficult situation of end-of-life care and possible death of cancer. **Results** The five survey response items and the importance of death and dying related survey items of the FACE-TC survey overall showed no significant differences between the age groups 14-17 and 18+ and the majorities of both groups had similar indications in their response options. **Conclusions** There is no present clear evidence that there is a major difference between adult and adolescent/children’s judgement and decision making as well as adolescents between ages 14-17 and ages 18+. End-of-life decision-making and care needs to be implemented, researched, and practiced in order to ensure the health, well-being, and peace of adolescent cancer patients and their families. **Implications of Findings** Researchers and public health practitioners must take a part racial disparity in terms of death and EOL care. There is a lack of research and emphasis on social determinants of health considerations for this public health issue. Needs assessments and evaluations should be conducted by public health practitioners and psychologist researchers. Continuing to implement interventions and conduct research with adolescents in their key developmental periods is essential to ensuring adolescents have a voice and autonomy in EOL decision making and care.

Objectives

The specific aims of the project include:

- Determining if there are differences between responses of adolescents with cancer between younger adolescents (the ages of 14 equal to or less than 17 years) versus older adolescents (ages 18 equal to or less than 21 years) regarding their end-of-life care, as measured by five advanced care planning survey items.
- Understand the importance of specific items related to death and dying by comparing data for younger adolescents (the ages of 14 equal to or less than 17) to older adolescents (ages 18-21).

The objectives of the project include:

- To examine patient-reported end-of-life values and needs of adolescents with cancer for ages 14-17 and ages 18-21 in terms of response items related to the importance of death and dying.
- To understand data on adolescent decision making that supports adolescent’s right to be involved in health care and end-of-life decision making.

Methods

Parent Study:

- Cross-sectional survey (Lyon Advanced Care Planning Survey) based on the 2-group randomized clinical trial design for Family Centered Pediatric Advance Care Planning for Teens with Cancer (FACE-TC) intervention.
- Between July 2016-April 2019 adolescents with cancer and their families were recruited from 4 tertiary care pediatric hospitals including Akron Children’s Hospital, St. Jude Children’s Research Hospital, University of Minnesota Masonic Children’s Hospital, and Children’s National Hospital.
- The trial consisted of 8 visits over 2 years.

Sample Population:

- The inclusion criteria for adolescents consisted of cancer diagnoses at any stage, awareness of the diagnoses, ages 14-21 years, English speaking, not in foster care, developmentally delayed, depressed, homicidal, suicidal, nor psychotic.
- In terms of recruitment, research assistants consulted with patients’ primary oncology physicians and then proceeded to approach potentially eligible participants face-to-face during hospital outpatient visits and stays.
- Adolescents were randomized to the FACE-TC intervention or treatment by using a computerized 2:1 ratio.
- In the FACE-TC group, session 1 included the Lyon ACP Survey, which is the survey used in this project.
- Results were reported in the Lyon FACE-TC ACP survey that were conducted in session 1.

Methods Cont’d

Procedures - Lyon ACP Survey items selected from Initial Findings

- The measures included five advanced care planning survey items related to future health plans, an Advance Directive, who the adolescent would want to be involved in decision-making.
- 7 Response items on a central question regarding the importance of death and dying.

Analysis

- Secondary and quantitative analysis of data between younger adolescents (14-17) and older adolescents (18-21) using SPSS.
- Chi square test was used to analyze differences by age group as well as frequencies, percentages, and p-values.

Results

Key Findings

Across these ages there showed no significant differences between the age groups and the majority of both groups had similar indications in their response options.

- Frequencies showed both age groups wanting honest answers from adolescents’ doctors.
- The importance of family/friends visiting AYA patients in the event that they were dying for both age groups.
- Both age groups had not written down any thoughts on their future health plans.

Minor Findings

The only significant differences included that more adolescents ages 14-17 had not heard about an Advance Directive or living will such as the Five Wishes, compared to the ages 18-21.

Table 1. Importance of Death and Dying Related Survey Items - Frequencies of Adolescent Responses for Survey by Age Group at Session 1 (N=80) – 3 Out of 7 Response Items

How important would each of the following be to you if you were dealing with your own dying?	Age 14-17 years (N=42)	Age 18+ years (N=38)	All Ages Combined (N=80)	P-value*
	N (%)	N (%)	N (%)	
a. Family/friends visiting you				
Very important	34 (81.0)	35 (92.1)	69 (86.3)	0.518
Somewhat important	6 (14.3)	2 (5.3)	8 (10.0)	
Neither important nor unimportant	1 (2.4)	1 (2.6)	2 (2.5)	
Do not know	1 (2.4)	0 (0.0)	1 (1.3)	
b. Being able to stay in your own home				
Very important	15 (35.7)	12 (31.6)	27 (33.8)	0.533
Somewhat important	16 (38.1)	18 (47.4)	34 (42.5)	
Neither important nor unimportant	5 (11.9)	2 (5.3)	7 (8.8)	
Not very important	5 (11.9)	4 (10.5)	9 (11.3)	
Not at all important	0 (0.0)	2 (5.3)	2 (2.5)	
Do not know	1 (2.4)	0 (0.0)	1 (1.3)	
c. Honest answers from your doctor				
Very important	41 (97.6)	36 (94.7)	77 (96.3)	0.602
Somewhat important	1 (2.4)	2 (5.3)	3 (3.8)	

Table 2: Chi-Square Test for Ages 14-17 and Ages 18+ Items Death and Dying Survey Items

Chi-Square Tests			
	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	351.333 ^a	306	.038
Likelihood Ratio	125.200	306	1.000
Linear-by-Linear Association	26.278	1	<.001
N of Valid Cases	30		

Results Cont’d

Table 3. Frequencies of Adolescent Responses for Survey by Age Group at Session 1 (N=80) – 2 Questions out of the 5 Advanced Care Planning Survey Items

Question	Age 14-17 years (N=42)	Age 18+ years (N=38)	All Ages Combined (N=80)	P-value*
	N (%)	N (%)	N (%)	
1. Have you ever written down any thoughts about your future health plans?				
Yes, definitely	1 (2.4)	2 (5.3)	3 (3.8)	0.901
Very probably	1 (2.4)	0 (0.0)	1 (1.3)	
Probably	2 (4.8)	3 (7.9)	5 (6.3)	
Probably not	7 (16.7)	4 (10.5)	11 (13.8)	
Definitely no	29 (69.0)	27 (71.1)	56 (70.0)	
Do not know	2 (4.8)	2 (5.3)	4 (5.0)	
2. Have you ever heard about and completed an Advance Directive or living will, such as the Five Wishes?				
Have heard about and completed	1 (2.4)	1 (2.6)	2 (2.5)	0.115
Have heard about but not completed	11 (26.2)	19 (50.0)	30 (37.5)	
Have not heard about	28 (66.7)	16 (42.1)	44 (55.0)	
Do not know	2 (4.8)	2 (5.3)	4 (5.0)	

Discussion

Strengths

- Largest EOL survey of adolescents with cancer and their families.
- Measures were valid and reliable in the likelihood of findings directly influencing clinical practice in a positive way.

Limitations

- Data was not collected for different cancer types.
- Participants have different responses, needs, and circumstances.
- There was a lack of diversity in participant data. 78.5% of participants were White out of the eligible/participating dyads.

Recommendations

- Health inequities influencing EOL decision making abilities and access to care is a huge area for public health researchers and practitioners to explore further.
- There needs to be more funding and focus on this area’s research gap and social determinants of health considerations.
- There is a need for interdisciplinary approaches to EOL given the developmental period of AYA patients.
- Clinicians and stakeholders must work with AYA patients and prioritize the importance of having their voices heard.

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