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Tell Me How You Feel: An Examination of Adolescent Oncology Patients and Their Families' Use of Emotionally Valent and Salient Words in Discussing End-of-Life Care

INTRODUCTION

The words used by adolescents and their caretakers were generally positive with a Adolescent Advanced Care Planning (ACP) is difficult valence mean of 5.92. When examining the top 10 most used words, the average to navigate. While ACPs have demonstrated valence was 6.31. The 10 most used words with their valence are shown below. improvements in care and 96% of chronically ill adolescents want to share in decision making, they ca be difficult to initiate.^{1,2} Parents and healthcare providers alike have indicated that end-of-life discussions are difficult to have to children.^{3,4}

One cited reason for not initiating talks about ACPs in pediatric practices is due to unpredictable responses, with fears of causing emotional distress.⁵ However, individuals typically rate their own ability to cope with death and dying as higher compared to others.⁶ The FAmily CEntered ACP for Teens with Cancer (FACE-TC) study was conducted to test the use of structured interviews to discuss ACP between adolescents with cancer and their family members.⁷ When in the FACE-TC intervention, adolescents and their family members were three times more likely to be in agreement regarding end-of-life treatment preferences compared to the control group with no additional cited emotional distress during the encounter.⁸

We wanted to examine what was said during the intervention to gauge participants' emotional states.

METHODS

FACE-TC transcripts were examined using the Affected Norms of English Words (ANEW) lexical dictionary to examine emotional language. The ANEW database quantifies the valence, how negative or positive an emotion is using a 1 to 10 scale with 10 being very positive.⁹

30 transcripts from the FACE-TC study were examined averaging 7,000 words total. Of these words, 16,130 total words were also in the ANEW database. Certain words ("patient," "mom," "dad," and "like") were removed from the analysis since they were used to refer to an individual or were used as word fillers.

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RESULTS

can	Word	# Words	Valence	Word	# Words	Valence
in ,	Know	975	6.93	Life	352	7.27
	Think	884	6.41	Cancer	324	1.50
	Me	718	8.06	Kind	274	7.59
	Want	417	5.25	People	259	7.33
	Time	364	5.31	Good	241	7.47



A word cloud was created using www.wordcloud.com to visually represent the 100 most frequently used words during the FACE-TC sessions. The color represents the valence of the word with red being a valence score of 1 (very negative) and green being a valence score of 10 (very positive). The size of the word represents its frequency in the transcripts.

These finding was consistent with previous studies examining written statements of individuals with terminal illnesses or who are on death row, the emotional valence of language was positive and increased in positivity closer to time of death.^{10,11,12} While psycholinguistics cannot be a substitute for assessing an individual's state of mind, this demonstrates that talking about death and dying is more positive than previously feared. Given the benefits associated with having end-of-life discussions and ACP, shifting perceptions regarding this topic may encourage healthcare providers to initiate conversations with their patients.

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CONCLUSIONS

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