Journal of Adolescent Health 54 (2014) 710–717

ELSEVIER

JOURNAL OF
ADOLESCENT
HEALTH

www.jahonline.org

Original article

A Longitudinal, Randomized, Controlled Trial of Advance Care Planning for Teens With Cancer: Anxiety, Depression, Quality of Life, Advance Directives, Spirituality

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Article history: Received July 13, 2013; Accepted October 28, 2013

Keywords: Adolescent; Advance care planning; Advance directive; African-American; Cancer; Communication; Decision making; End of life; Family intervention; Pediatric palliative care

ABSTRACT

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

Methods: Adolescent (age 14–20years)/family dyads (N = 30) with a cancer diagnosis participated in a two-armed, randomized, controlled trial. Exclusion criteria included severe depression and impaired mental status. Acceptability was measured by the Satisfaction Questionnaire. General Estimating Equations models assessed the impact of FACE-TC on 3-month post-intervention outcomes as measured by the 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, and advance directive completion.

Results: Acceptability was demonstrated with enrollment of 72% of eligible families, 100% attendance at all three sessions, 93% retention at 3-month post-intervention, and 100% data completion. Intervention families rated FACE-TC worthwhile (100%), whereas adolescents' ratings increased over time (65%–82%). Adolescents' anxiety decreased significantly from baseline to 3 months post-intervention in both groups ($\beta = -5.6$; $p = .0212$). 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% of FACE-TC adolescents vs. no controls). Oncologists received electronic copies. Total Spirituality scores ($\beta = 8.1$; $p = .0296$) were significantly higher among FACE-TC adolescents versus controls. The FACE-TC adolescents endorsed the best time to

IMPLICATIONS AND CONTRIBUTION

Family-Centered Advance Care Planning for Teens With Cancer is the first randomized clinical trial of pediatric advance care planning 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 pediatric advance care planning forward.

Disclaimer: The contents of this study are solely the responsibility of the authors and do not necessarily represent the official views of the National Center for Advancing Translational Sciences or the National Institutes of Health or the American Cancer Society.

Conflicts of Interest: The Lyon Advance Care Planning Survey is copyrighted by the first author and is available free of charge by request at mlyon@childrensnational.org. Linda Briggs, MSN, RN, receives no royalties for training facilitators to use the Respecting Choices tool. This training is provided by the non-for-profit Gundersen Health System, which does charge fees for the on-line and face-to-face trainings.

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http://dx.doi.org/10.1016/j.jadohealth.2013.10.206

bring up end-of-life decisions: 19% before being sick, 19% at diagnosis, none when first ill or hospitalized, 25% when dying, and 38% for all of the above.

Conclusions: Family-Centered Advance Care Planning for Teens With Cancer demonstrated feasibility and acceptability. Courageous adolescents willingly participated in highly structured, in-depth pediatric advance care planning conversations safely.

Palliative care (PC) currently exists in the context of a changing health care delivery system in which death is medicalized. Four of five children with complex chronic conditions in the United States die in the hospital [1]. Among children with cancer 72% of those without PC died in the ICU versus 21% of those with PC [2]. Advance care planning (ACP) is one dimension of palliative care that provides support in decision making about limiting burdensome medical interventions and advance directives. Adolescents want a voice in choices for their end-of-life (EOL) care, if they cannot speak for themselves [3–5]. Avoidance of EOL conversations can lead to miscommunication and disagreements, which may result in families charged with neglect, court battles, and even legislative intervention [6]. The Institute of Medicine's report, *When Children Die,* recommends that these conversations become a routine and structured part of standard of care [7]. The landmark SUPPORT study demonstrated that focusing on advance directives alone is insufficient to ensure that patients' treatment preferences are honored at EOL [8]. Building on these findings, research identified the critical importance of including the surrogate decision maker in structured conversations with the patient about the patients' goals for EOL care [9]. Nevertheless, ACP conversations are frequently not initiated before a medical crisis because of the strong emotions evoked [10] or fear of taking away hope [11], which contrasts with empirically based research that early palliative care can instill hope [12], maintain psychological well-being [13], increase congruence in treatment preferences between patients and their surrogate decision makers [14], prolong survival [15], and improve quality of life and mood among surviving relatives [16]. Spiritual quality of life is another important aspect of PC among dying children [7], because being diagnosed with a life-limiting illness can inspire reflections on death and spirituality.

Only three structured pediatric ACP (pACP) programs are reported for adolescents with complex chronic conditions. First is FOOTPRINTS, a model of pACP and coordination specific to patients with muscular dystrophy (age 8–21 years) [17]. Second is Family-Centered (FACE) Advance Care Planning, a model specific to adolescent patients with human immunodeficiency virus (HIV) (age 14–21 years) and their family. This was the first protocol to test pACP using a randomized clinical trial [13,18,19]. The third is FACE for Teens With Cancer (FACE-TC), which adapted the HIV protocol for teens with cancer [20]. (The development of FACE-TC is described in Appendix 1, which can be found in the on-line version of this article.) Immediate outcomes for FACE-TC replicated the previous findings from FACE [13] of increased congruence in treatment preferences between adolescents and their families, decreased decisional conflict, and a willingness to limit treatments in some situations compared with controls [20].

Standard hospital practice is for hospital administrative personnel to inquire about the presence of an advance directive when the patient is hospitalized, only if they are ≥18 years of age. Under the age of 18 years, the pACP process is often triggered during a medical crisis. Many physicians believe that this is too late to begin this conversation [21].

Challenges to pACP unique to adolescents include their emerging intellectual and emotional maturity [22]. Nonetheless, evidence supports the practice of allowing adolescents to make decisions about their health. Cognitive capacities required to make informed treatment decisions do not differ from those of adults [23]. Many young adolescents have as mature an understanding of death as those aged ≥18 years [7]. Unique challenges also arise from the adolescent–family dynamic if there are disagreements in treatment preferences, particularly in the context of the adolescents' lack of legal authority to make treatment decisions under the age of 18 years in most states [6].

Cancer remains the leading illness causing death for adolescents [24]. In a review of 95 medical records of children with cancer who died, 53% had a "do not resuscitate" order at the time of death [25]. Effective EOL care is a public health issue because of cancer's high symptom burden and the potential to prevent suffering [26]. An age-appropriate communication model that includes adolescents with cancer and their families in making decisions about medical treatments that frequently precede death was recently tested for efficacy in a randomized controlled trial [21]. The 3-month post-intervention outcomes of this study are reported here.

Our aim was to demonstrate the feasibility, acceptability, and safety of a highly structured pACP conversation with teens with cancer and their families, which incorporated communication of the results to their oncologist and placement of an advance directive in the medical record. We explored the influence of pACP on spirituality. Predetermined benchmarks for acceptability were enrollment >50% of eligible families, attendance >80% at all three sessions, retention >80% at 3-month follow-up, completeness of data >90%, and >90% rating sessions as worthwhile. Legal guardian(s) or surrogate decision maker(s) are referred to as family/families from this point forward.

Hypotheses at 3-month post intervention follow-up were:

(1) Adolescent/family dyads in the intervention will maintain or increase quality of life and psychological adjustment compared with controls, a marker for safety.
(2) Adolescents in the intervention group will be significantly more likely to engage in a robust pACP session, followed by completion of an advance directive accessible in their medical chart, compared with controls.
(3) Adolescents in the intervention group will have significantly increased spirituality compared with controls.

Methods

From January 2010 through July 2012, we conducted a small, randomized, controlled, clinical trial in which adolescent/family