

## Original Article

# Advance Care Discussions: Pediatric Clinician Preparedness and Practices

Amy Sanderson, MD, Amber M. Hall, MPH, and Joanne Wolfe, MD, MPH

Department of Anesthesiology, Perioperative & Pain Medicine (A.S., A.M.H.) and Department of Medicine (J.W.), Boston Children's Hospital, Boston; and Division of Pediatric Palliative Care (J.W.), Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, Massachusetts, USA

---

## Abstract

**Context.** Few data exist regarding clinician preparedness to participate in advance care discussions (ACD) and the practices surrounding these discussions for children with life-threatening conditions.

**Objectives.** We sought to understand pediatric clinician preparedness to participate in ACD and the practices surrounding these discussions.

**Methods.** A survey was administered to assess clinician attitudes and behaviors regarding ACD.

**Results.** Two hundred sixty-six clinicians (107 physicians and 159 nurses) responded to the survey (response rate 53.6%). Seventy-five percent of clinicians felt prepared to participate in ACD. Most clinicians believed they were prepared to express empathy (98.8%), discuss goals of care for an adolescent patient (90.3%), and elicit a parent's hopes (90.3%). Conversely, several felt unprepared to discuss resuscitation status with school-aged (59.7%) and adolescent (48.5%) patients and to conduct a family conference (39.5%). The most frequent topics addressed were: parents' understanding of the patient's illness (75.5%), primary goals of the parent (75.1%), and the parents' understanding of prognosis (71.1%). Conversely, the topics least commonly discussed were as follows: belief system of the patient/family (22.0%), patient's hopes (21.2%), and the patient's perceptions of his/her quality of life (19.8%). Notably, 40% of clinicians believe that caring for patients with poor prognoses is depressing, and this was more common among less-experienced clinicians ( $P = 0.048$ ).

**Conclusion.** Many clinicians believe they are prepared to participate in ACD, but practices are not consistent with expert recommendations for optimal ACD. Educational interventions aimed at improving clinician knowledge, attitudes, and behavior, and greater clinician support may enhance health care provider ACD preparedness and skills. *J Pain Symptom Manage* 2016;51:520–528. © 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

Advance care discussion, pediatric palliative care, end-of-life

---

## Introduction

Advance care discussions (ACD) for children with life-threatening illnesses are essential to providing optimal patient care. Effective communication, including communication that occurs both before and during a medical crisis, is an essential component of quality palliative care. Clinicians, patients, and families agree that clear, honest, and effective communication is imperative for the optimal care of seriously ill

patients.<sup>1–3</sup> Moreover, the process surrounding ACD can affect patient and family perceptions of the quality of care.<sup>1,4</sup> Parental dissatisfaction with end-of-life (EOL) care has been associated with inadequate communication, specifically parents feeling uninformed and not understanding the cause of their child's death.<sup>5</sup> Conversely, families have reported a higher quality of care when advance care planning occurs, especially earlier in the disease process.<sup>6</sup> Unfortunately, both families and clinicians believe that

---

Address correspondence to: Amy Sanderson, MD, Division of Critical Care, Boston Children's Hospital, 300 Longwood Avenue, Bader 634, Boston, MA 02115, USA. E-mail: amy.sanderson@childrens.harvard.edu

Accepted for publication: October 28, 2015.

ACD often happen too late in the course of a patient's illness.<sup>7,8</sup> Recognizing the need to improve EOL communication, several palliative care experts have developed consensus recommendations to assist clinicians.<sup>3,9–11</sup>

Although there have been small qualitative studies of pediatric clinician perspectives and practices regarding ACD,<sup>12,13</sup> most studies in the literature have focused on adults.<sup>14–17</sup> We sought to understand pediatric clinician preparedness to participate in ACD as well as the practices surrounding these discussions for children with life-threatening conditions.

## Methods

As part of a larger study, a Web-based self-report questionnaire was administered to assess clinician perspectives regarding ACD and the Do Not Resuscitate order. The institutional review board at Boston Children's Hospital (BCH) approved the study.

### Study Population

Physicians and nurses from practice settings where ACD typically take place were surveyed to collect data regarding their attitudes and behaviors concerning these discussions. Eligible respondents included intensive care unit (ICU), oncology, and cardiac ICU (CICU) attending physicians, fellows, hospitalists, nurses, and advanced practice nurses. Study sites included the Medical/Surgical ICU, Medicine ICU, CICU, and Oncology ward at BCH and the outpatient Oncology Service at the Dana-Farber Cancer Institute.

### Data Collection

Eligible clinicians were sent an e-mail explaining the study, and participation was requested. The survey was conducted using Web-based survey software ([SurveyMonkey.com](http://SurveyMonkey.com), Palo Alto, CA). A link to the online survey and a link to opt out of the study were provided. Three reminder e-mails were sent at two-week intervals to all nonresponders. Clinicians who declined participation were not contacted further. Identifying information such as e-mail addresses, names, and IP addresses was not linked to the respondents' answers. Persons who completed the survey were entered into a raffle to win one of three gift cards to a local restaurant. Data were collected during March, April, and May of 2010.

### Survey Instrument

The survey instrument comprises 148 items. Survey domains were derived from clinician and parental focus groups regarding attitudes and behaviors about ACD and resuscitation status orders.<sup>18</sup> Closed-ended

items were adapted from a number of existing surveys, and other items were developed de novo, according to guidelines by Streiner and Norman.<sup>19–22</sup> The instrument was evaluated for face validity by faculty at BCH and the Dana-Farber Cancer Institute. The survey was pilot tested and revised according to feedback from cognitive debriefing. A majority of questions were close-ended, with categorical responses or Likert scales.

### Main Outcome Measures

*Preparedness to Participate in ACD.* Physicians and nurses were asked to rate their sense of preparedness to be actively involved in ACD in general, as well as 18 specific aspects of ACD. There were five response choices ranging from "poor" to "excellent." For the purposes of this study, if a clinician chose the response categories "good," "very good," or "excellent," then they were considered to be prepared. Alternatively, if a clinician chose "fair" or "poor," then they were considered to be unprepared. Specific items included conducting a family conference, giving bad news, eliciting an emotional reaction from a patient/parent, expressing empathy, discussing prognosis, eliciting a patient/parent's hopes and worries, discussing overall goals of care including resuscitation status, with school-aged and adolescent patients, and discussing child goals of care including resuscitation status with a parent.

*Approach to ACD.* Study participants were asked about their practices regarding ACD, including the logistics of the meeting. In particular, clinicians were asked how often 16 recommended elements are a part of ACD with response categories from "never" to "always," including selection of a private room, assuring that there are enough chairs, attendance by all interested parties, phones/pagers held by someone not in the meeting, introductions of attendees, defining the purpose of the meeting, sitting at eye level, using good eye contact, reviewing the patient's condition, avoiding medical jargon, listening to the patient/family without interruption, repeating what the patient/family has said, using the words death and dying (if applicable), providing specific recommendations, asking the patient/family if they have any questions, and allowing silence if grief is expressed. In addition, clinicians were asked how often 16 topics were addressed during ACD with five response choices ranging from "never" to "always". Specific items included patient and parent/guardian understanding of the patient's illness, prognosis, hopes, worries, goals for ongoing medical care, social support, belief system, patient symptoms, patient quality of life, and resuscitation status.

Download English Version:

<https://daneshyari.com/en/article/2729729>

Download Persian Version:

<https://daneshyari.com/article/2729729>

[Daneshyari.com](https://daneshyari.com)