Differences between Pediatricians and Internists in Advance Care Planning for Adolescents with Cancer

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Objective To evaluate differences between pediatricians and internists in the practice of and barriers to advance care planning (ACP) for adolescent patients with cancer.

Study design A self-reported questionnaire was administered to assess the practice of ACP, advance directives, and barriers to ACP for adolescent patients with cancer. All 3392 Japanese board-certified hematologists were surveyed, and 600 hematologists (227 pediatricians, 373 internists) who take care of adolescent patients with cancer with decision-making capacity were analyzed.

Results If a patient's prognosis for survival was <3 months, pediatricians were significantly less likely to discuss ACP with their patients than internists, including discussions regarding the patient's medical condition (59% vs 70%), the patient's understanding of his/her medical condition (55% vs 66%), do not attempt resuscitation orders (17% vs 24%), and ventilator treatment if the patient's condition worsened (19% vs 25%). More than 75% of hematologists (both pediatricians and internists) discussed all ACP topics with patients' families. Similarly, with regard to advance directives, pediatricians were less likely than internists to discuss cardiopulmonary resuscitation (24% vs 47%) and the use of ventilators (31% vs 51%), vasopressors (24% vs 42%), and antibiotics (21% vs 31%) with their patients. Both pediatricians and internists discussed these issues more often with patients' families than with patients, especially cardiopulmonary resuscitation (98%) as well as the use of ventilators (98%) and vasopressors (91%).

Conclusions Pediatricians were less likely than internists to discuss ACP and advance directives with patients, and both pediatricians and internists tended to discuss ACP and advance directives more often with patients' families. *(J Pediatr 2017;182:356-62).*

Advance care planning (ACP) is a voluntary process of discussion about future care among patients, their families, and healthcare providers; it is considered one of the most important interventions for quality end-of-life care. ACP takes into consideration an individual's concerns and wishes, values important to the patient, personal goals for care, understanding the illness and its prognosis, and preferences for the type of care or treatment that may be beneficial in the future, as well as its availability. ACP requires communication between patients, their families, and healthcare providers and is best done with consideration of the patient's relationships and culture, which will then drive specific medical treatment decisions that can be recorded in an advance directive.

ACP with adolescent patients is gaining increasing attention but is a difficult area of practice. Adolescent patients have expressed a desire and the ability to share their values, beliefs, and preferences for treatment at the end of life.[1-4] A previous study found that 75% of adolescent patients with cancer believed it was appropriate to discuss end-of-life decisions even before their condition worsened.[5] The American Academy of Pediatrics recommends that pediatricians should give serious consideration to each patient's autonomy.[6] However, some care providers exclude adolescent patients from ACP because these teens have been deemed not legally competent to make decisions for themselves.[7]

The care provision in pediatrics is more family centered and sometimes focuses not on the patients, but several aspects of the effects of end of life on the entire family. In comparison, the adult setting is more autonomous, and adult patients are likely to be seen alone with structured care.[8] Differences in the practice of and barriers to ACP and advance directive between pediatricians and internists have not been explored. In hematology, especially in hemato-oncology, pediatricians and internists both have opportunities to see adolescent patients who have similar disease backgrounds, such as leukemia or lymphoma.

The aim of the present study was to clarify differences in the practice of and barriers to ACP and advance directive for adolescent patients with cancer between pediatricians and internists. In addition, the study aimed to determine current ACP and advance directive practices among hematologists with regard to adolescent patients with cancer.

ACP	Advance care planning
CPR	Cardiopulmonary resuscitation
DNAR	Do not attempt resuscitation

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Methods

A self-reported questionnaire was administered to assess practices regarding ACP and advance directive, as well as barriers to ACP for adolescent patients with cancer. The Institutional Review Board of Osaka City University Medical School approved this study (3126).

All hematologists certified by the board of the Japanese Society of Hematology, the oldest and leading hematology academy in Japan, were eligible to complete the questionnaire. The total number of hematologists was 3392, and this included both pediatricians and internists.

Mailing information for all board-certified hematologists was obtained from the Japanese Society of Hematology's web page.[9] All eligible physicians were sent a letter explaining the study and containing a questionnaire, and requesting their participation. Hematologists for whom a mailing address was not available (n = 178) were excluded from the study. A reminder letter was sent 4 months after the initial survey mailing, except when initial letters were returned because of incorrect addresses. Identifying information, such as names and addresses, was not linked to respondents' answers. Data were collected from October 2015 to May 2016.

Of the hematologists eligible to participate in the study, responses were obtained from 910 (247 pediatricians, 663 internists; response rate 27%). Data were then analyzed for 600 hematologists who indicated that they had experience of taking care of adolescent patients with decision-making capacity (227 pediatricians, 373 internists).

The survey instrument consisted of 82 items. Items were adapted from existing surveys[10,11] after minor revision following discussions with specialists, namely 3 palliative care physicians, 2 pediatricians, 2 nurses, and 2 psychotherapists. The survey was pilot tested by a convenience sample of 15 physicians, including both pediatricians and internists, and revised according to feedback from cognitive debriefing. All questions were close-ended, requiring categorical responses or rating on a Likert-type scale.

Outcome Measures

Practice of ACP. The survey items concerning individual physician's practices with regard to ACP were separated into 2 parts. The first part examined physicians' practices of ACP with adolescents with cancer and included questions regarding how frequently physicians did each of the following if their patient's prognosis was >1 year or <3 months: (1) discuss the patient's medical condition; (2) verify the patient's understanding of his/her medical condition; (3) discuss the patient's prognosis; (4) discuss the goals of treatment and care; (5) promote sharing of the goals of treatment and care between the patient and his/her family; (6) discuss where treatment and care are to take place; (7) discuss do not attempt resuscitation (DNAR) orders with the patient; and (8) discuss ventilator treatment if the patient's condition worsens.

Physicians were required to answer these questions using a 5-point Likert-type scale: "always," "often," "sometimes," "rarely," or "never."

The second part of this section of the survey asked clinicians to answer the same questions, but with regard to discussions with patients' families rather than the patients themselves.

Participants were asked about the discussions they have with patients about advance directives at the end of life using the following binary question: "Do you usually discuss resuscitation and life-prolonging therapy with patients if their prognosis is less than 4 weeks?" Participants were also asked about the discussions they have with patients regarding cardiopulmonary resuscitation (CPR) and the use of ventilators, vasopressors, antibiotics, tube feeding, and intravenous fluids. The same questions were used to investigate participants' discussions of advance directives with patients' families.

Barriers to ACP. Using a 5-point Likert-type scale (always, often, sometimes, rarely, or never), physicians were asked to rate how often 29 potential barriers were actual impediments to ACP. These questions were created on the basis of a previous study.[11] Specific items assessing physician perception of barriers related to patient/family behaviors and practices included patient/family expectations, readiness to have the discussion, understanding of the medical issues and prognosis, and conflict between the patient and family members. Potential barriers related to physician behaviors and practices included concern about taking away hope or losing trust, not knowing the right things to say, lack of a relationship with the patient and/or family, not knowing the right time to hold the discussion, uncertainty about the prognosis, physician expectations, lack of readiness to have the discussion, lack of time, physicians not placing much importance on ACP, lack of training, ethical considerations, and lack of laws and/or guidelines.

Additional Covariates

Survey respondents were asked to report their specialty, their experience (years practicing), age, sex, and the number of dying patients under 18 years of age they have cared for over their entire career. In addition, they were asked to specify the type of medical facility in which they were currently working from the following choices: university hospital, children's hospital, cancer center hospital, other hospitals, rehabilitation center, clinic, or "other."

Statistical Analyses

Statistical analyses were conducted using SAS v 9.2 (SAS Institute, Cary, North Carolina). Demographic data were summarized using descriptive statistics. Group comparisons between pediatricians and internists were made using Pearson χ^2 test. In the present study, questions regarding ACP practices rated using Likert-type scales were dichotomized as follows: 0, "sometimes," "rarely," or "never"; 1, "always" or "often." Similarly, responses regarding barriers to ACP were dichotomized as a barrier frequency variable as 0, "sometimes," "rarely," or "never"; 1, "always" or "often." Although this system was used to