Pediatric Oncology Careproviders' Attitudes on and Perceptions of Assent

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ABSTRACT

Purpose

The purpose of this study was to describe pediatric oncology careproviders' attitudes and perceptions regarding including pediatric patients in decision-making discussions for cancer treatment.

Methods

Potential participants were identified via institutional staff listings and recruited via internal email addresses. Of 27 eligible participants, 16 completed an anonymous online survey consisting of 12 questions, yielding a response rate of 59 percent.

Results

Of the 16 careproviders surveyed, 75 percent strongly agreed that it is valuable to include pediatric patients in decision-making discussions. Those who did not find value in the practice still reported using multiple methods to assess for understanding and agreement in a child. Almost two-thirds (62.5 percent) began including children in decision making between the ages of seven and nine. All 16 careproviders indicated that they would proceed with cancer treatment if the child did not agree, but the illness was imminently life threatening, and the parents gave permission. Barriers reported in the study included the child's developmental level, differences in primary spoken language, parental preference, and the child's age.

Conclusion

Careproviders at our institution self-report to be practicing in line with the recommendations of the American Academy of Pediatrics. Next steps might include exploring ways for careproviders to educate parents on the rationale for including children in decision-making discussions. Additionally, finding effective strategies to identify and remove language barriers may improve communication.

INTRODUCTION

Informed consent in the adult population is a widely recognized and frequently discussed topic in medicine and bioethics. But how does the topic apply to the pediatric population? Recognizing that persons under the age of 18 may not legally consent but may have capacity and should have input as to what happens to their body, the concept of pediatric assent has evolved over the last 25 years. William G. Bartholome was one of the first pediatricians to explore the issue and draft recommendations related to informed consent in the pediatric popula-

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tion.[1] The American Academy of Pediatrics (AAP) Committee on Bioethics expanded on Bartholome's work by publishing a policy on assent in 1995.[2] Described in the policy are four minimum components of assent: (1) helping the patient achieve a developmentally appropriate understanding of his or her condition, (2) telling the patient what to expect with tests and treatments, (3) assessing the patient's understanding of the situation and the factors influencing the patient's response, and (4) attempting to determine the patient's willingness to accept the care. The policy recommends that clinicians seek both parents' permission and patients' assent. In the more recent literature, clinical ethicists such as Franco Carnevale have argued that children are capable of unique moral experiences, and recommend that parents and healthcare professionals make every attempt to relieve any moral distress experienced by children as a result of tests, procedures, or treatments in the healthcare setting by "attending meaningfully to their questions, objections, and possible protests."[3]

Since publication of the 1995 AAP policy on informed consent, studies have examined the knowledge and use of its recommendations by pediatric careproviders in specific subpopulations,[4] and in 2016 the AAP published a revised policy.[5] In a 2006 qualitative study, a questionnaire was administered to pediatric surgeons, anesthesiologists, and subspecialists regarding their knowledge of assent, the AAP policy, and their practice concerning assent.[6] It is significant that the surgeons surveyed in this study reported less often than the subspecialists in the study that they were aware of the components of assent. The surgeons were also less likely to be familiar with the AAP policy. Interestingly, only nine of 35 clinicians in the study reported always seeking a child's agreement to a care plan. In a 2010 study, a "quality of assent instrument" was utilized to retrospectively determine children's understanding of, and desire to participate in, oncology research trials that the children had participated in, in years prior. Nearly half of the children recalled having no, very little, or little involvement in the decision-making process regarding enrollment in the research trial.[7]

Interestingly, only nine of 35 clinicians in the study reported always seeking a child's agreement to a care plan.

Most of the studies we reviewed observed or described assent in pre-operative, pre-procedure, or end-of-life situations;[8] however, many serious decisions are made in the context of longitudinal pediatric care, a setting that has not received as much attention in the literature. In this context, it is argued that even young children can develop and voice their care preferences, as they have been exposed to disease and interventions.[9] In addition, children with chronic conditions benefit from increasing responsibility and participation in their own medical care, which will allow them the opportunity to develop self-reliance and positive self-care behaviors that will aid in their transition to becoming autonomous adult patients.[10]

For these reasons, we decided to examine pediatric decision making within the field of oncology, a field in which pediatric patients and their families have repeated interactions with a careprovider and must make significant decisions about treatment protocols that are often high risk. A 2002 study observed the use of assent in 14 pediatric oncology care conferences when leukemia treatment was discussed. The authors found that a very small amount of careproviders' communication was directed toward pediatric patients.[11] However, all but two of the 14 clinicians sought some degree of input from the children regarding clinical trials. Although this study reported that the clinicians were seeking agreement to treatment, the dynamics of the preceding conversations were not described. The situations were complicated by the fact that a child's assent is required for research, but not for clinical care, making it difficult to determine whether assent was obtained simply because it was required, or because the careprovider found value in including the child. Overall, little is known about the dynamics of decision-making discussions in pediatric oncology or about the attitudes of careproviders regarding including pediatric patients in decision making.

Although there were gaps in the literature related to the content and process of assent discussions, during the project's iterative process, the authors learned of a new initiative at our institution that was designed to improve education on obtaining assent. Faculty are implementing didactic workshops with instruction and simulation of assent discussions. In addition, we discovered that our institution utilizes a structured pediatric assent form, which includes information about the child's diagnosis and treatment plan, and has spaces for parents and children older than seven to sign to indicate their assent for treatment. With this standardized form and the amount of information covered during treatment discussions, it became apparent that there is not typically a great deal of variety in these discussions. Thus, the focus of this study is less on the assent process, and more on careproviders' attitudes and their perception of the value of including pediatric patients in decision making. Another purpose of this study is to describe the barriers that careproviders encounter to when they attempt to include pediatric patients in making decisions about their treatment.

Regarding challenges to including pediatric patients in decision-making discussions, all of the careproviders indicated that the child's developmental level could pose some challenges.

METHODS

Survey Population

There are 43 pediatric hematology/oncology careproviders at the Medical College of Wisconsin (MCW), including physicians, nurse practitioners, and certified physician's assistants. Our inclusion criteria stipulated that careproviders must be actively seeing patients for an oncology diagnosis and conducting discussions regarding assent for treatment. Careproviders who reviewed the content of the survey prior to the study were excluded from the study. Of the 43 careproviders, 27 met inclusion criteria.

Instrumentation

The survey included 12 questions created by the research team to explore gaps in previous studies. Questions were a mix of Likert scales, multiple-choice questions, value-rating scales, and open-ended questions. It was reviewed by two careproviders in the Division of Pediatric Hematology, Oncology, and Bone Marrow Transplant at MCW and a group of 15 medical students at MCW, to assess for readability, bias, and appropriateness of content.

Survey Process

This study was designated an "exempt" status by the MCW Institutional Review Board. Following the grant of an exemption, the concept of the study was introduced at a Pediatric Hematology/Oncology Department meeting. Potential participants were recruited individually via internally available email addresses. A direct survey link was provided in the recruitment email. One follow-up email was sent. The data were collected anonymously via *Survey Gizmo.com*. The link was open for responses for two months, after which it was closed for data analysis.

Data Analysis

Data were analyzed item by item using descriptive statistics such as the frequency of responses. Observations were made about the responses depending on the characteristics of the respondent, such as the number of years in practice and the type of degree held.

RESULTS

Of the 27 careproviders who were sent invitations to participate, two responded they did not currently see cancer patients, and so were not eligible to complete the survey. Two participants opened the survey link but did not complete any of the questions. Of the 16 participants who began the survey, all completed all of the questions. This yielded an overall response rate of 16/27 or 59.2 percent.

Demographics

Of the participants, 69 percent identified as a doctor of medicine (MD) or doctor of osteopathy

(DO), while the remaining 31 percent were nurse practitioners (NP) or certified physician assistants (PA-C). Half of the respondents identified as female; half as male. The mean and median number of years of practice in pediatric oncology were 11 to 15 years. See table 1 for the distribution of years in practice.

Pertinent Findings

Of the study participants, 75 percent (*n* = 12/16) strongly agreed that it is valuable to include pediatric patients in decision-making discussions along with their parents or guardians for cancer treatment. There were 12.5 percent (*n* = 2/16) who agreed with this statement; notably, 12.5 percent strongly disagreed. Careproviders who strongly disagreed were NPs/PAs.

None of the careproviders indicated that they would begin including pediatric patients in discussions if they were under the age of seven. However, 62.5 percent (*n* = 10/16) indicated that they would begin including patients between the ages of seven and nine. See table 2 for the full distribution of ages of inclusion in decision making.

TABLE 1. Years in pediatric oncology practice, including fellowship

Years	%	Responses
0-5	12.5	2
6-10	18.8	3
11-15	31.3	5
16-20	25.0	4
21-25	0.0	0
26-30	0.0	0
31+	12.5	2
Total:		1

TABLE 2. Ages at which respondents begin to include pediatric patients in decision making

Ages	%	Responses
Under 7 years of age	12.5	2
7-9 years of age	62.5	10
10-11 years of age	6.3	1
12-13 years of age	6.3	1
Over 14 years of age	6.3	10
Don't typically include in discussions	0.0	0

Regarding challenges to including pediatric patients in decision-making discussions, all of the careproviders indicated that the child's developmental level could pose some challenges. Other barriers reported were parental preference for the child to not be included (*n* = 15/16), the child's primary language not being English (*n* = 13/16), the acuity of the child's illness (*n* = 10/16), and the child's age (*n* = 9/16). Only two careproviders indicated that a time constraints were a challenge. Write-in responses indicated that it was a challenge if the parents' primary language was not English, and if the patient did not want to be included in decision making.

Of the options that were provided regarding beliefs on important aspects of a visit, careproviders put the highest priority on parents understanding their child's diagnosis, parents understanding the proposed treatment, parents agreeing with the proposed treatment, questions from either the parents or the child, and fears or concerns from either the parents or the child. When it came to the child understanding the proposed treatment, 25 percent of those surveyed (*n* = 4/16) indicated it was "very important," while 62.5 percent (*n* = 10/16) believed that it was "important," and the remaining 12.5 percent (*n* = 2/16) were split between "neutral/indifferent" and "somewhat important." Very similar results were seen in response to the importance of the child agreeing to the proposed treatment, with one additional careprovider indicating "neutral/indifferent."

Although the least importance was placed on the child's understanding of and agreement to the treatment plan, in follow up, all of the careproviders indicated that they ensured that a child understands and agrees. The most common methods for assessing understanding reported by the careproviders were asking the child directly (*n* = 11/16) and having the child repeat information back (*n* = 11/16). Almost as prevalent was watching for nonverbal signals from the child, such as nodding (*n* = 10/16). Some write-in responses included verbally quizzing the child (n = 3/16), asking the child if she or he had questions (*n* = 1/16), and having the child work with a child life specialist to express feelings through art or play (*n* = 1/16). As far as assessing genuine agreement, 87.5 percent of careproviders (*n* = 14/16) stated that they asked the child directly, and 75 percent (*n* = 12/16) indicated that they would have the child sign a document. Of the 50 percent who said they would utilize nonverbal signals to assess agreement, only 6.26 percent (*n* = 1/16) would use that as their only technique. The rest combined it with the aforementioned techniques.

Because our institution's practice includes using a standardized assent for treatment form to guide discussions, along with signature lines for the pediatric patient and parents, we inquired about careproviders' opinions regarding its purpose and value. Careproviders could select multiple responses.

Most commonly, 62.5 percent (*n* = 10/16) stated that its purpose is to indicate agreement to the proposed treatment. Other popular choices were to indicate understanding (*n* = 7/16) and to have documentation for legal purposes (*n* = 6/16). Interestingly, only one careprovider stated that the purpose of the form is to begin transitioning the child into an autonomous adult patient. Other notable write-in responses were that signing the form is useful for therapeutic buy-in, to help the child understand the seriousness of the discussion, or simply that it is required for participation in clinical trials.

When questioned about the value of the patient and parents signing an assent for treatment form, the most frequent response in a "select all that apply" style question was that the signature is valuable to the institution (*n* = 12/16, 75 percent). The second most frequent response was that the signature is valuable to the pediatric patient (*n* = 9/16, 56 percent). When analyzing the distribution of the responses, only two of the careproviders answered that the signature was valuable solely to the patient, but five careproviders indicated that it was valuable solely to the institution. The rest answered various combinations of value to the careprovider, the patient, the patient's parents, the institution, or the institutional review board. One of the 16 careproviders (6.25 percent) did not feel that the signature was valuable to anyone.

The final question of the survey was scenario-based, in an attempt to apply careproviders' opinions regarding assent in a clinical matter. Careproviders selected from several situations in which they would proceed with cancer treatment without having some of the assent process complete. See table 3 for the distribution of careproviders' responses to the various scenarios.

DISCUSSION

Overall, most careproviders in the study reported that they found value in including pediatric patients in decision-making discussions for cancer treatment. This led to the conclusion that, in pediatric oncology, at this institution at least, the ideals and practices of careproviders fall in line with AAP recommendations and the requirements for clinical trial participation. For example, the earliest age of inclusion in discussions reported in this study was seven to nine years. This finding correlates with the AAP suggestion that children have some potential for logical thought beginning at age seven, and that seeking their assent can help "foster moral growth."[12] Almost all of the careproviders in this study indicated that they at least began to include patients at this point.

Interestingly, although two careproviders indicated they strongly disagreed that including pediatric patients in decision-making discussions is valuable, all of the careproviders indicated an age by which they began including children in these discussions. It is unclear the reasons that careproviders engaged in obtaining assent if they did not find value in doing so. It may be that the careproviders were simply practicing to an expected standard of care. Further research addressing this question is warranted, especially given that our research team could not hypothesize a reason in which differences existed between nurse practitioners and physicians.

Similarly, some careproviders indicated that they were indifferent towards the importance of a child's understanding and agreeing to a proposed treatment plan, but all of the careproviders indicated multiple ways that they assessed for these items during a discussion. In contrast to simply including the patient in the discussion, seeking assent, at least for participation in a clinical research trial, is federally mandated. This may be why some careproviders were continuing practices they personally did not think were important.

In the recently updated AAP policy statement on pediatric assent for treatment purposes, as well as for research, it is stated that dissent for research by a minor should be respected, but that a waiver

TABLE 3. Distribution of respondents' responses to scenarios

Scenarios	%	Responses
If the child is too sick to sign the form, but the parents give permission	■ 100.0	16
If the child is not present at the decision-making discussion, but the parents give permission	■▨ 56.3	9
If the child does not agree, but has an illness that is immanently life threatening	■▨ 62.5	10
If the child is too young to comprehend the impact of the signature on the assent form, but the parents give permission	■ 100.0	16

may be granted if direct benefit may only be obtained in the context of research.[13] Our findings regarding situations in which careproviders would proceed with treatment without some components of assent corresponded with these recommendations. Careproviders were unanimous that they would proceed with treatment in situations in which an assent form could not be physically signed, but the parents had given permission. This finding suggests that these careproviders believed that assent was more about the process of providing information, and assessing for understanding and agreement, rather than a simple signature on a document. There was less uniformity when it came to proceeding with a treatment if the child was not present at the assent discussion, but the parents had given permission. Again, this finding suggests that these careproviders usually did wish to educate the child and include the child in the decision-making process. An interesting scenario that the survey asked careproviders to consider was when a child dissents, but has an illness that is imminently life-threatening. Overall, 62.5 percent (n = 10/16) in this study said that they would still proceed with cancer treatment. Decision making in this case likely centered around the evaluation of risks and benefits to the child, in the context of the child's developmental level. In young children, the AAP suggests not giving the child an option, if the child's dissent would not be respected, regardless. In adolescents, the suggestion is to engage in thoughtful discussion to elucidate the patient's goals and values, and to be aware of state legislation on adolescent treatment refusal.[14] However, refusal would only be considered when a curative option was unlikely and burdens were high.

Overall, this study found that most pediatric oncology careproviders at this institution reported that it was valuable to include pediatric patients in decision-making discussions.

Regarding the barriers to pediatric inclusion, it was fascinating that only 12.5 percent of the careproviders in the study felt that they were challenged by the amount of time available to have these decision-making discussions. Time is a factor that is often described as interfering with quality physician-patient interaction, but it seems that adequate time for treatment decision making was a strength of the pediatric oncology department at this institution. However, there was a significant burden of barriers reported in the survey, such as the child's developmental level, the parents' preference for the child to be excluded, or language barriers. Although our institution constantly has in-person, telephone, or video interpreters available, we did not inquire whether careproviders in this study utilized these services. Thus we cannot draw a conclusion on the effects of a language barrier versus difficulties with video or audio quality, or availability of an interpreter with the specific language required.

Regarding the implementation of the assent simulations and workshops for pediatric oncology fellows at our institution, more research may be indicated to see how careproviders' practice and opinions change over time. Per a 2016 cross-sectional survey of pediatricians, a formal ethics curriculum in residency was not found to correlate with increased ethical knowledge using a validated instrument.[15] However, a 2015 literature review found an overall theme to be a desire for more "real-life context" in ethics training, and an interdisciplinary approach over the span of medical school, residency, fellowship, and practice. This review also found that most residents preferred informal discussions with their mentors about cases, rather than a formal, lecture-based ethics curriculum.[16]

The educational initiative at the authors' institution regarding simulated discussions related to treatment and assent is a promising sign for an integrated curriculum. Perhaps our institution could implement an evaluation tool to determine the residents' learning needs, and the strengths and weaknesses of the ethics training they are receiving.

The limitations of this study include a small sample size at a single academic medical center. The survey questionnaire that was utilized was not previously validated by other studies. Another potential limitation is that participants' self-report may not reflect their actual behavior.

Overall, this study found that most pediatric oncology careproviders at this institution reported that it was valuable to include pediatric patients in decision-making discussions. Even those participants who did not find value in the practice still reported multiple methods that they assess for understanding and agreement in a child. The careproviders' priorities regarding decision-making discussions were described, and barriers to communication were elucidated. The next steps in this area of study might include exploring ways for physicians to educate parents on the rationale for including children in discussions. Additionally, there seems to be room for improvement in communication between careproviders and patients in the context of language barriers.

NOTES

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12. AAP, Committee on Bioethics, "Informed consent," see note 5 above.

13. Ibid.

14. Ibid.

15. J.C. Kesselheim et al., "Ethics knowledge of recent paediatric residency graduates: the role of residency ethics curricula," *Journal of Medical Ethics* 42 (2016): 809-14, doi:10.1136/medethics-2016-103625.

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