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Ethics in Pediatric Endocrinology: Curriculum for Fellows and Faculty

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Abstract

Introduction: In clinical practice, ethical dilemmas are frequently faced by pediatric endocrinologists. This initiative's objectives were to (a) determine if endocrine fellows and faculty perceived that an effective ethics curriculum existed and (b) evaluate whether case-based modules would be an effective tool for ethics education. **Methods:** Participation was sought from eight large pediatric endocrine programs (home programs and affiliates of the Pediatric Endocrine Society's Ethics Committee members) after the distribution of eight case-based modules (geared mainly to fellows) and pre- and postsurveys. Questions examining self-reported knowledge (K) of the ethical pillars (beneficence, nonmaleficence, autonomy, and justice), attitudes (A) towards these, and the individual's likelihood of utilizing them in clinical practice (P), in addition to the need for/benefit of this curriculum, were assessed using a 5-point Likert scale. **Results:** Six out of eight programs participated, with surveys completed by fellows ($n = 29$), faculty ($n = 7$), and advanced practitioners ($n = 3$). Of the respondents, only 20.3% believed an effective ethics curriculum was already in place. After module completion, KAP scores improved, with the greatest improvement seen in knowledge scores. Additionally, 94.9% of respondents strongly agreed ($n = 26$) or agreed ($n = 11$) that the curriculum would be a valuable addition to fellowship training. All faculty believed that the curriculum was helpful in imparting ethical principles of clinical practice. **Discussion:** The findings suggest that this curriculum would be useful in knowledge advancement of ethical principles and could fulfill a long-standing need to provide clinical ethics education for faculty and fellows.

Keywords

Ethics, Autonomy, Beneficence, Justice, Ethical Principles, Pediatric Endocrinology, Nonmaleficence

Educational Objectives

By the end of this activity, learners will be able to:

1. Define the ethical pillars of clinical practice: beneficence, nonmaleficence, autonomy, and justice.
2. Analyze each case in the context of the ethical pillars.
3. Formulate an appropriate management based on the ethical dilemma in each case.

Introduction

Over the past 5-10 years, the scope of pediatric endocrinology, like that of other clinical medical subspecialties, has expanded. With this expansion, practitioners are being increasingly called upon to use existing treatments to manage new patient populations, such as gonadotropin-releasing hormone analogues, testosterone, and estrogen in youth with gender dysphoria or hormone therapies to enhance the height of an otherwise healthy child, in addition to implementing new and sometimes experimental technologies such as fertility preservation. Such scenarios often raise ethical concerns.

Cases of children with special needs who may be subjected to hormonal-based therapies may also be fraught with ethical issues. For instance, in 2007, a supratherapeutic dose of estrogen was administered along with bilateral mastectomy and hysterectomy to a 10-year-old girl with static encephalopathy who was named Ashley. Collectively, the aforementioned techniques have been termed the *Ashley treatment*.¹ The parents argued that these interventions would allow them to more easily care for their daughter as she grew older, would preclude her from experiencing menstrual discomfort, and, in addition, would

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Appendices

- A. Introduction to Ethics in Pediatric Endocrinology.pptx
- B. Ethical Issues Regarding Endocrine Management in the Care of Disabled Children.pptx
- C. Ethical Issues in Prescribing Growth Hormone.pptx
- D. Ethical Issues Regarding Childhood Obesity.ppt
- E. Ethical Issues Regarding the Poorly Adherent Patient With Type I Diabetes Mellitus.pptx
- F. Ethical Issues in Children With Disorders of Sex Development.pptx
- G. Ethical Issues in Transgender Medicine.pptx
- H. Ethical Issues in Fertility Preservation in Klinefelter Syndrome.pptx
- I. Ethical Issues in Fertility Preservation in Turner Syndrome.pptx
- J. Ethics in Pediatric Endocrinology Facilitator Resource Tool.docx
- K. Pre- and Posttest Questionnaire.doc

All appendices are peer reviewed as integral parts of the Original Publication.

prevent the possible discomfort associated with having large breasts, reported to be common in the family. Similarly, there have been cases described of caregivers requesting hormonal suppression in children with autism and sexually inappropriate behaviors.²

Practitioners may face significant challenges in considering the interests of both the patient and the caregiver(s) in determining the best care plan for the patient. In addition, many practitioners believe that they do not have the background or training in clinical ethics with which a case may be dissected. The Pediatric Endocrine Society (PES) Ethics Committee recognized that while practitioners both during and after training may face such dilemmas as outlined above, the American Board of Pediatrics' content specification,³ despite outlining a curriculum for ethics in research, has not provided a curriculum outline for ethics in clinical practice. Hence, the current curriculum was designed to fulfill an unmet need.

Case-based discussion modules designed to raise ethics awareness were first created approximately 5 years ago and progressively added to the PES website; however, they were underutilized. These modules included the following: Ethical Issues Regarding Endocrine Management in the Care of Disabled Children (Appendix B), Ethical Issues in Prescribing Growth Hormone (Appendix C), Ethical Issues Regarding Childhood Obesity (Appendix D), Ethical Issues Regarding the Poorly Adherent Patient With Type I Diabetes Mellitus (Appendix E), Ethical Issues in Children With Disorders of Sex Development (Appendix F), and Ethical Issues in Transgender Medicine (Appendix G). Recently, two new modules, Ethical Issues in Fertility Preservation in Klinefelter Syndrome (Appendix H) and Ethical Issues in Fertility Preservation in Turner Syndrome (Appendix I), were created. All eight modules were edited and approved by the PES board of directors. Subsequently, we conducted a survey assessing whether pediatric endocrine fellows and faculty felt that there was adequate ethics training in place and whether these modules helped fulfill an unmet need in their ethics education.

Methods

Target Audience

Practitioners of pediatric endocrinology (fellows at all levels of training, advanced practitioners, and attending physicians) were invited to participate. Practitioners from programs with which a member of the PES Ethics Committee was affiliated were invited to participate. Eight programs were invited, and six participated in the pilot testing (75% response rate). Participating programs included Children's Mercy Hospital, Nationwide Children's Hospital, Children's Hospital Colorado, Seattle Children's Hospital, Hassenfeld Children's Hospital of New York University, and the Children's Hospital of Philadelphia.

For the pilot phase, each participant was sent a module (topic selected at random; Appendices B-I), with instructions to complete a pretest survey prior to viewing the module and then a posttest survey (Appendix K). Using a 5-point Likert scale, eight paired questions were piloted in the pre- and postanalytical phase examining self-reported knowledge (K) of the ethical pillars (beneficence, nonmaleficence, autonomy, and justice), attitudes (A) regarding importance of these principles, and likelihood of applying these principles to clinical practice (P), as well as perceived need for/benefit of this curriculum. Though a KAP study has traditionally been a tool to explore changes in the KAP of communities and large populations, it was used for the pilot since it encompassed not only an assessment of the participant's knowledge but also an application of the ethical pillars that in effect represents a higher-order process, suitable for case studies.^{4,5}

Participants were encouraged to complete their module under the guidance of a faculty moderator; however, those who were unavailable for those sessions completed them individually. We chose this method rather than formal didactics on the ethical pillars of clinical practice (beneficence, nonmaleficence, autonomy, and justice) as case-based learning has been shown to be an effective strategy for optimizing clinical practice and in promoting knowledge retention among physicians.⁶

Preparation

Though, in general, no acquaintance with clinical ethics is necessary prior to commencing a module, for faculty moderating these discussions, prior module review may facilitate more discussion and debate. This recommendation is based on feedback obtained during the pilot phase. In addition, we have added an introductory PowerPoint presentation (Appendix A) to introduce users to the overall curriculum. Fellows at all training levels may benefit from these modules, which may also prove useful for individuals needing a refresher on applying the ethical pillars of beneficence, nonmaleficence, autonomy, and justice to cases.

Results

Surveys were completed by fellows ($n = 29$), faculty ($n = 7$), and advanced practitioners ($n = 3$) at six of the eight large pediatric endocrine programs (75% response rate), as stated above. Only 20.3% of the respondents felt that an effective ethics curriculum existed at the time of the survey. KAP scores improved after participants completed the modules, with knowledge scores showing the greatest improvement. As shown in the Figure, 94.9% of respondents strongly agreed ($n = 26$) or agreed ($n = 11$) that the curriculum would be a helpful addition to pediatric endocrine fellowship training. Additionally, all faculty felt that the curriculum would be helpful for faculty to learn about ethical principles applicable to clinical practice.

Figure. Perceived curriculum effectiveness by respondents (based on Likert-scale response).

Feedback

The feedback obtained at the time of conducting the posttest survey was positive, with comments in general attesting to the usefulness of the modules in facilitating discussion around their presented cases.

The amount of time required varied (generally 30-60 minutes) based on the audience and level of discussion.

Specific comments on the posttest survey included the following:

- “Great discussion! We should have regular case scenario and discussions like this.”
- “Good case!”
- “Great module!”
- “Nice job! Brought up good questions for discussion.”
- “Would be helpful to have more discussion and debate within the session! Otherwise good topic!”

Discussion

Given that ethical dilemmas are commonly encountered by pediatric endocrinologists, through this initiative we have identified and are addressing an important gap in training. The ethics modules that have been created can be used by learners at the graduate medical education level as well as by individuals posttraining. The latter includes faculty, physician assistants, and advanced practice nurses interested in advancing their knowledge of clinical ethics in pediatric endocrinology. Formatting of the modules conforms to the six criteria for scholarship: clear goals, adequate preparation, appropriate methods, significant results, effective presentation, and reflective critique (adapted from *Scholarship Assessed*⁷).

The evaluations in the pilot phase of the curriculum were positive overall. Practitioners at all levels (fellows, advanced practitioners, attending physicians, and faculty) felt the modules were useful. They reinforced our initial perception that there is great need for more education of both trainees and physicians in practice on clinical ethics in pediatric endocrinology. Of note, learners completing the module without a faculty moderator felt that more discussion within the modules would have been helpful; thus, a facilitator's guide (Appendix J) has been created. This will enhance the educational experience for the learner, facilitate group discussions, and standardize the clinical approach to such cases.

Although the original six modules were created several years ago and located on the PES website (accessible to members), web usage data showed a relatively low number of views. In order to increase usage, we intend to send the curriculum to pediatric endocrinology fellowship program directors to facilitate utilization by trainees and faculty at their respective institutions. We will also disseminate information about this curriculum in the PES monthly newsletter. In its monthly Ethics Corner section, we will spread awareness of the curriculum and solicit feedback as to potential additional topics of interest in order to create new modules to add to the curriculum. Furthermore, we intend to send out an annual survey aiming to assess utilization, in addition to other aspects of the curriculum, such as perceived benefit and suggestions for improvement and for future topics to include.

At this time, the existing modules cover only eight areas. Although this is not an exhaustive list of topics in which ethical dilemmas may arise in pediatric endocrinology, we believe that with the valuable knowledge gained from these modules, a learner can acquire some experience with which to approach other cases with similar ethical dilemmas in clinical practice. We plan to update the current modules as new medical information emerges and paradigms change.

In summary, we believe that this formalized curriculum fulfills an unmet need and equips the learner to become more comfortable forming a management plan based on the pillars of clinical ethics. This is especially important as the scope of pediatric endocrinology expands with the incorporation of various topics in which ethical dilemmas arise in the provision of care.

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Ethical Approval

Reported as not applicable.

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