Nursing Ethics
19(4) 581–589
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10.1177/0969733012448348
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Pediatric consent: Case study analysis using a principles approach

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Abstract
This article will explore pediatric consent through the analysis of a clinical case study using the principles of biomedical ethics approach. Application of the principles of autonomy, nonmaleficence, beneficence, and justice will be dissected in order to attempt to establish resolution of the ethical dilemma. The main conflict in this case study deals with whether the wishes of an adolescent for end-of-life care should be followed or should the desire of his parents outweigh this request. In terminal cancer, the hope of early palliative care and dignity in dying serve as priorities in therapy. Application of the moral principles to both sides of the dilemma aided in providing an objective resolution to uphold pediatric consent.

Keywords
Consent, case study, decision-making capacity, end of life, ethics, pediatric oncology

Introduction—case presentation

Max is a 17-year-old Caucasian male previously diagnosed with acute lymphocytic leukemia at age 7. In the past, he has endured multiple relapses of his cancer requiring chemotherapy every 2 weeks followed by periods of remission. This regimen was difficult for Max because of the nausea, vomiting, and pain associated with treatment. After remission for 3 years, Max was admitted to the pediatric intensive care unit (PICU) with complaints of bone pain causing inability to bear weight on his legs and increasing respiratory distress. At this time, it was discovered that he had osteosarcoma. Despite oxygen and continuous positive airway pressure (CPAP) support, aggressive chemotherapy, and localized high-dose radiation for 1 month, lung metastases and organ failure were found. The health care team scheduled a family meeting to discuss the fact that there are no further treatment plans likely to produce cure or remission.

The physician explains that the cancer is rapidly progressing and unresponsive to treatment. Max feels that he has endured more than enough suffering from previous therapies and would like to preclude further extraordinary treatment and have a "do not resuscitate" (DNR) order in his chart. The team deemed Max competent and believed his mature decision was made with full understanding of his treatment options and prognosis.

Max's parents are holding on to the hope that further aggressive treatment and dialysis will prolong his life and offset the side effects of the chemotherapy and therefore refuse to have the DNR order upheld. They want further chemotherapy and radiation options though Max has poor prognosis for survival. Max is

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resolute that he has "suffered enough" and that he "NEVER wants to become a vegetable on life support." His parents refuse to comply with palliative therapy at this time until more time is given for different treatment options to work. Within 2 weeks, Max's condition deteriorates requiring emergency intervention. His parents wanted the health care team to provide all interventions despite Max's request. He is resuscitated, intubated, and started on dialysis. He is no longer conscious. The bedside nurse suggests consulting palliative care and the ethics committee to resolve the parent–child conflict because Max's parents want to escalate care rather than follow the wishes of their son.

Agents, interests, and dilemmas

Max seems determined to eliminate his continuing suffering at the end of his life. His interests lie with stopping futile treatment and taking control of death on his own terms. Max's parents' interests lie in preserving his life despite the knowledge that improvement is highly unlikely. The PICU Medical Team in this case includes nurses, physicians, oncology specialists, child life specialists, and social workers. The interest of the team is to holistically support Max and his family in their health care decision-making without coercion. Their goal is to achieve consensus within the family and to prevent Max from further suffering if possible. The medical institution has interests to ensure that standards and policies are followed, negative attention is avoided with prompt conflict resolution, and all clients are satisfied with the care they receive. There are multiple dilemmas in this particular case such as futile care, pediatric advance directives, consent/dissent to treatment by a competent minor, and decision-making capacity.

Theoretical analysis of the case

The four principles approach is based on the premise that there are a set of basic principles that provide the structure to support basic moral norms and actions in society.[1] It also surmises that the powers of reason and the guiding concepts of autonomy, nonmaleficence, beneficence, and justice establish duties we have toward others and ourselves. These moral principles can be adapted as guidelines to analyze ethical dilemmas. In this case, they will be applied to support the argument for or against pediatric consent and provide an objective framework for determining a resolution to the conflict.

Analysis of position 1

The first position rests with the parents' opposition to Max's choice to discontinue medical treatment and to forfeit extraordinary resuscitative efforts due to the inevitability of his health decline. This is based on the notion that as Max is a minor and has not reached the legal age of majority, his parents have the right to pursue any treatment they feel may have any chance of prolonging his life (in the US, a minor cannot consent if they are under 18). It is supported by the general notion that parents are the most capable people to act in a minor's best interest because they are more competent than adolescents to make medical decisions.

Beauchamp and Childress[1] have defined the principle of respect for autonomy as the norm that emphasizes freedom from both controlling interference by others and from limitations, such as inadequate understanding, that might prevent meaningful choice. Though it may seem that the parental decision in this case denies Max's autonomous choice in his treatment, parental autonomy legally supersedes such choices when a minor (under age 18) is involved. That is, until they reach the legal age, children can partner in decision making but their autonomy has yet to displace the locus of control from their parents. Max has been identified as a mature adolescent with a chronic illness, experience with treatments, and knowledge to make informed medical decisions. Even with these facts, his parents are elevated to the position of seizing his short-term autonomy and denying his decision-making capacity.

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According to Whitney et al.,[2] the family has a strong claim to decisional priority over the child and the physician, when the chance of cure is slight, and there is a reasonable choice between aggressive therapy and palliative care. In this case, the parents take this decisional priority, and it is their duty to help Max make choices that are as informed as possible in order to value his autonomy. Unguru et al.[3] have stated that children's vulnerability relates directly to their limited decision-making capacity and their parents' interests must lie in protecting their best interests as they see fit. Max dissents to the escalation of care, but it could be argued that children are less reflective about choices while their parents are able to evaluate long-term outcomes. Because it is difficult for children to contemplate the future at the expense of the discomforts in the present, parents "shoulder all social, emotional, and legal obligations."[4] Therefore, it can be concluded that ethical obligations defer to parental autonomy and decision making. Minors do not have the legal right to refuse treatment approved by their parents unless courts intervene, and therefore, it remains the responsibility of the parents to garner consent and explore reasons for dissent.[5] In a study by Lee et al.,[6] it was argued that the model of parental permission and pediatric consent supported by the American Academy of Pediatrics (AAP) was less sound in clinical work. They favored a model of "constrained parental autonomy," which gave children no decision-making authority but was designed to protect the child without them being "treated solely as a means" and require parents to provide their children with "goods, skills, liberties, and opportunities necessary to become autonomous adults" (p. 727).

Yet, it may be suggested that respect for children as persons requires respect for their well-being. This concept can be described as beneficence, the moral obligation to protect others against harms (nonmaleficence).[1] The debilitating sequelae of chemotherapy, radiation, and dialysis treatments are performed with the intent of prolongation of life even though they inflict harm in the process. Any act that purposely reduces an individual's survival can be seen as inflicting harm. The parental argument to continue these treatments and escalate the intensity of care does violate nonmaleficence but only for the hope of beneficence. The treatments that Max considers extraordinary are, in his parents' opinion, customary options for aggressive cancer treatment that will prolong their time together. According to Beauchamp and Childress,[1] "harmful actions that involve justifiable setbacks to another's interests are, of course, not wrong." Thus, choosing life over the side effects of treatment could be perceived as an easier option for these parents. Therefore, their intent appears to guide this resolution to overcome their child's dissent to therapy.

Analysis of position 2

Max gives the health care team consent for palliative care and a DNR order to prevent escalation of treatments once his body starts to deteriorate. This second position relies on the fact that Max is a competent minor who fits the criteria established by the AAP policy statement. This criterion guides health care providers to honor informed consent directly from the minor in order to respect their decision-making capacity.[7] Since there is evidence that Max has sufficient knowledge, maturity, and understanding to dissent to further treatment, his decision should be taken seriously and be given priority.

Autonomy is the most important aspect of this argument because the conflict in decision-making capacity lies in whether Max meets the criteria for having his consent honored. Under usual circumstances, the principle of autonomy requires the acceptance of the free and informed choices of competent patients. Subsequently, it could be argued that Max's health care experience enabled him to have a mature capacity beyond his age to be independent in his medical choices. Though legally able to provide informed consent for Max, his parents hold an unreasonable expectation of what further treatment will do and therefore may be emotionally distracted and unable to provide competent judgment and decision-making authority.

The debate over the role of pediatric consent and dissent in health care has yet to be settled since the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research created the concept in the 1970s. However, the AAP Committee on Bioethics states that health care providers, who

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recognize the importance of consent in decision-making, empower the minor's respect for autonomy and establish the fullest sense of their capacity.[8] Max's fervent request against further escalation of treatment can be deemed ethically binding. Furthermore, most states apply the common law doctrine of "mature minors." This concept allows an adolescent to provide informed consent for medical decisions if they are able to understand and appreciate the extent and consequences, risks and benefits, and nature and context of the situation. Indeed, as Zawistowski and Frader[4] found, there have been cases where discontinuance of care for dying adolescents was upheld in court using best interest and substituted judgment with emphasis on the wishes of the minor involved. Hence, even though most parents attempt to provide for the best interests of their children, end-of-life decisions present a difficult challenge to parents' ability to ascertain what is really in the best interest of the adolescent. End-of-life decision-making should therefore default to the competent adolescent because their parents are unable to separate their own interest or those of the family from the needs of the patient.

The principles of beneficence and nonmaleficence further support the argument against the desires of Max's parents. The health care team has clearly established that there is no reasonable hope of benefit from continuation or escalation of current care, therefore "any expense, pain, or other inconvenience is excessive, and it is probably obligatory not to treat" (p. 124).[1] The proposed treatments actually cause harm without any benefit to the patient who will ultimately still die despite the therapy. Max has previous experience with aggressive anticancer treatment and therefore he is the best authority on what causes suffering and what is bearable. Whitney et al.[2] have found that sometimes families are unwilling to accept end-of-life care because it acknowledges the death of their loved one but it also submits that child to a "quixotic quest for cure" that leads to "a long nightmare of dying." Following this argument, the only way to ensure beneficence when death is inevitable is to provide comfort and respect for the dying, which Max self-advocates in his wish for palliative care. Similarly, a DNR order will not cause harm because the natural progression of his illness will have caused his death, whereas there may be some suffering inflicted in the process of resuscitative efforts. Though Max's parents feel they must fight to prolong his life by any means, the futility of this fight violates their intention of beneficence. Application of beneficence and nonmaleficence to treatment strategies overwhelmingly supports palliative care as opposed to futile treatment.[2]

Conclusion

The application of ethical principles to this case study analysis supports position 2 that the ethical outcome supersedes the legal obligation to gather decision-making authority from Max's parents. It also takes into account the possible feelings of the health care providers on the medical team. These feelings, as Oberle and Hughes[9] found, are an example of moral distress among doctors and nurses that was related to "witnessing suffering" and was identified as a core problem in providing care. Austin et al.[10] also found in their study of futile care that "prolonged treatment past any hope of survival was cited as 'torture' by nurses." Though this is an emotionally driven case, Max's parents should respect his autonomy and his wishes for end-of-life care. Alternatively, legal advocacy for Max may become most important when ongoing medical treatment is deemed to be entirely futile or is at the expense of other important goals and values.

Since the parental argument for continuance of care has been trialed, another family meeting should be scheduled and the attendance of clinical psychologist and palliative care team should be requested. The fact that Max's parents have seen that their decision has not benefited his health may lead to them being more willing to come to terms with Max's condition. In fact, substituted judgment calls for parents to base their decisions on the patient's own values and previously voiced opinions, thereby upholding some form of patient autonomy in their final decision.

This case study analysis has championed the best available end-of-life treatment for Max and upheld the power of pediatric consent in determining authority for decision-making capacity. The moral norms of

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autonomy, nonmaleficence, beneficence, and justice guided conflict resolution for the presented ethical dilemma. Though it is difficult to generalize the findings here to all similar situations, it is important to mediate a compromise between the opposing interests of a moral dilemma while attempting to be objective in one's advocacy plan.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Conflict of interest

The author declares that there is no conflict of interest.

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