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CONLEY ESSAY

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Keeping Joey at the Center of the Conversation: Ethical Considerations in a Challenging Pediatric Case

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After experiencing morning headaches, vomiting, and increasing lethargy for about 3 months, Joey, 12 years of age, was found to have a medulloblastoma. He had surgery to remove as much of the tumor as possible. Joey had a postoperative MRI that showed no focal metastatic sites. His treatment plan called for radiation immediately following the surgery and then chemotherapy.

Joey's oncologist, Dr. Burnet, told his mother that an ongoing study was investigating the use of lower-than-standard doses of craniospinal radiation in a subset of children like Joey. The study was testing the hypothesis that the lower radiation dose followed by high-dose chemotherapy would produce the same survival rates as the standard high radiation dosage while reducing the neurocognitive side effects of the radiation.

When Joey and his mom met with Dr. Burnet, his mom told Dr. Burnet that she did not want Joey to participate in the experimental treatment regimen. Joey didn't say anything during the meeting, but on the way home he told his mother that he wanted to be a part of the experimental treatment study. She asked him why. Joey, who had always been a curious kid, loved school, and was proud of his ability to excel at his studies, said, "Mom, they think this is going to be better than what they're doing now. I don't want to be a cancer-free dummy..."

Joey's mother and father were separated, and, although Joey lived with his mom, his father remained close to both of them and involved in his son's life. When Joey's mother told him about the treatment decision they were being asked to make, Joey's dad said, "I think we should let Joey decide. He's old enough to understand what the risks and possible benefits are. It's his life." The mother and father were alone, and Joey's mom was fighting back tears. "I can't say yes to this experiment; I just want our son to live," she said.

The three of them went to Dr. Burnet together so that they all could hear what Dr. Burnet had to say. In the meantime, they learned as much as they could from the Internet, and what they were able to find just confirmed what Dr. Burnet had said. This time Joey spoke up in the office, telling Dr. Burnet that he wanted to participate in the lower-dose radiation study.

“Because this regimen is experimental,” Dr. Burnet told Joey’s folks, “Joey’s assent is really important, but it’s best for everyone if all of you to agree to the treatment. I’m sure you can see why it’s critical that everyone be on board when you’re facing a possibly life-changing decision. We have a physician-ethicist on staff,” Dr. Burnet continued, “who might be able to help you sort out some of the questions you have. The key one, as I see it, is who gets to decide what is in Joey’s best interest. Would you like to meet with our physician-ethicist, Dr. Klein?”

Response

On the surface, one might think that pediatrics is simply adult medicine in younger people. A trained clinician however, knows that there are differences so distinct that many physicians devote their entire lives to just treating this select population. In addition to obvious anatomical, pharmacokinetic, and developmental differences, the *practice* of medicine is also slightly different. Physicians not only treat their patient but must also interact with the patient’s parents. Indeed pediatric cases can be more complex and emotionally demanding, and decisions are often made by individuals other than the patient. These difficult cases often intersect the field of bioethics in the important areas of research ethics and consent. Physicians may feel overwhelmed by the ethical complexities of a particular case, and just as a pediatrician may refer their patient to an oncologist, an oncologist may likewise ask for a clinical ethicist to lend expertise as they navigate the various moral quandaries.

One such example could be the following case. Joey is a 12-year-old boy found to have a medulloblastoma. Following a successful surgery that removed all visible tumor and a post-surgical workup showing no metastasis, his treatment plan called for immediate radiation and then chemotherapy. Dr. Burnet, Joey’s oncologist, informed Joey and his family that Joey could participate in an experimental treatment regime that was determining if a lower radiation dose would produce the same survival rates as the higher standard radiation dosage while reducing the neurocognitive side effects. Because several moral issues are at play in this case, Dr. Burnet requested Dr. Klein—a physician-ethicist—be included in the subsequent discussions. This paper provides a structure that Dr. Klein could follow as he explores the various ethical aspects of this case. First a basic framework for the consultation will be mentioned, followed by a brief examination of the study. Prior to a comprehensive discussion of pediatric consent, the family will be reminded of their decision-making roles and how they can enhance the discussion. This will lead to an exploration of Joey’s values and interests, ending with a similar examination of his parents’ values and interests.

While Dr. Burnet may be familiar with an ethics consultation, it is likely that Joey and his family are not. It is therefore critical that Dr. Klein establish realistic expectations about the ethics consultation and flesh out the various issues that need to be addressed. Joey and his family should understand that the role of Dr. Klein is similar to Dr. Burnet’s in that each offers expertise, clinical ethics and oncology respectively, with the goal of improving Joey’s care. In leading the discussion, and because there initially appears to be a conflict between Joey and his mother, Dr.

Klein should employ a style consistent with mediation. In doing so, Dr. Klein should create a space where all parties are encouraged to tell their story and express their interests in an environment free of judgment. Along those lines, Dr. Klein should not take Joey and his parents' initial statements as clear unambiguous expression of their positions. Instead, Dr. Klein should be encouraged to solicit and explore each individual's underlying values and interests that support those initial positions. This will provide Dr. Klein some room to maneuver as he attempts to build a consensus that, given any initial conflicts, advances everyone's understanding of what is best for Joey. Joey and his family should also understand the limit of Dr. Klein's and Dr. Burnet's roles. While Dr. Klein is interested in Joey's health and recovery, he is only contributing to this very narrow aspect of Joey's care.

Critical to the limit of Dr. Burnet's role is his relationship to the study that Joey may participate in. For Joey to participate, it is absolutely essential that Dr. Burnet not be involved in any aspect of the study. If this were violated, Dr. Burnet would have to simultaneously balance the interests of Joey against the interests of the study—an inherent conflict of interest best avoided by a morally sound physician-scientist. Equally critical is that the study be approved by an Institutional Review Board—an institutional body responsible for ensuring the scientific merit and balancing the risks and benefit of the research protocol.

While Drs. Klein and Burnet bring additional expertise to the discussion, Joey and his family should be reminded of the various competencies they contribute. The thought that Joey has a brain tumor can be incredibly frightening and difficult to process, much less manage. Joey should be reminded that his surgery was successful and without complications and that his family has remained a strong cohesive unit despite his parents being separated. This is no small task and deserves explicit recognition. Also commendable is their initiative to educate themselves about Joey's disease and the treatments available. Perhaps most praiseworthy is Joey's participation in this process. His parents should be extolled for encouraging their son to take additional ownership of his life by contemplating the consequences of his decisions. Joey should equally be praised for participating and should continue to take advantage of his parents' guidance.

Of particular importance to this case is the role of pediatric assent—or Joey's decision to participate in a specific treatment plan. Part D of the Common Rule details the relevant federal regulations. For the study in question, Joey's treatment would be greater than minimal risk—defined as “the probability and magnitude of harm or discomfort anticipated in the research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests” [1]—but also present the prospect of direct benefit to Joey. Participation of this type of study requires (1) Joey's assent and (2) informed permission from his parents [2].

In contrast to adult informed consent where the goal is self-determination, pediatric assent prioritizes the best interests of the child over principles of autonomy. Indeed

parental permission originates from beneficence and the nonmaleficence of unjustified risks, whereas pediatric assent reflects the respect of the child's *developing* autonomy. More practically, this position maintains that minors lack the life experience necessary to prevent actions that they may regret later. Providers may therefore be justified to intervene when necessary and proportionally restricting their liberty for the purposes of promoting their health and minimizing harms [3]. Critical to note is that the absence of dissent does not qualify as assent.

Turning our attention to Joey, it's critical to ascertain his values, preferences, and goals of treatment. Joey is presented as a curious kid who excels at his studies, and Dr. Klein should be encouraged to engage Joey's character to best determine Joey's values. Dr. Klein could continue the discussion by exploring why Joey remained silent during his initial meeting with Dr. Burnet. There are limitless reasons of varying significance for why he was initially quiet, but to ignore it would be a disservice. Joey states that he doesn't "want to be a cancer-free *dummy*..." (emphasis added), indicating he places significant importance on and is very averse towards any reduction in his cognition. Dr. Klein should be especially sensitive to Joey's '...' when describing why he wants to participate in the experimental treatment regimen. The pause could be insignificant, but it might indicate there is more to be solicited and requires further investigation. Equally important is Dr. Klein's verification that Joey understands his medical condition and the study to the best developing cognitive abilities.

Integrating all this information, Dr. William Bartholome defined the four elements of pediatric assent as (1) a developmentally appropriate understanding of the disease; (2) disclosure of the proposed intervention and what it involves; (3) an assessment of the child's comprehension of the information provided and the influences that may sway the child's evaluation of the situation; and (4) a solicitation of the child's expression to willfully accept the intervention [4]. A discussion between Drs. Klein and Burnet should occur beforehand to determine what extent of understanding, of which specific elements in the experimental protocol, would be required for Joey to assent. Dr. Klein should be particularly aware of two beliefs that adolescents may occasionally exhibit; (1) a bias toward the nearer future—Joey may choose immediate benefits (cognitive ability) over his interest of remaining cancer free in the distant future—and (2) the invulnerability hypothesis wherein Joey may underappreciate his own vulnerability to certain types of harm [3]. There is no indication that Joey displays either behaviors, however it would be advisable that Dr. Klein be alert of these possibilities as he continues his consultation.

Similar to Joey, his parents' values, preferences, and goals of treatment should be solicited and explored. Parental involvement is critical, not only because society entrusts them to protect their children, but because Joey is literally dependent on his parents. Joey's father believes that he is "old enough to understand what the risks and possible benefits are". As previously recommended, Dr. Klein should resist temptation to accept this at face value and solicit specific examples that define Joey's father's position. Turning our attention to Joey's mother, she states that she "can't

say yes to giving *less* treatment” (emphasis added). Parental permission follows criteria similar to pediatric assent, namely it is critical that Joey’s parents understand the study to the best of their ability. To recommend the experimental treatment regimen Dr. Burnet, as an advocate for Joey’s health and recovery, would have to believe that both treatments are in clinical equipoise; a genuine uncertainty about which treatment is more efficacious. It therefore follows that the in this clinical scenario, and what should be clearly communicated to Joey’s mother, both treatments are believed to be *equal* when looking at survival rates.

The experimental treatment regimen *may* produce similar survival rates, or it may be more or less efficacious—this is what the study is trying to determine. What is believed is that the experimental treatment regimen would reduce the neurocognitive side effects. This tradeoff is the crux of the decision on whether to participate. Joey’s mother continues by saying “I just want our son to live.” This initial statement, at face value, appears to be in conflict with Joey’s goals of care. Whereas Joey places his cognition at a premium and appears to be concerned with recurrence secondarily, his mother seems to be less averse to the neurocognitive side effects of the treatment—valuing the prevention of recurrence more. To overcome this impasse Dr. Klein must be able to ascertain their fundamental values and goals of care, find common ground, and craft a solution that advances each stakeholder’s interest. Dr. Klein should be keenly aware that statements similar to Joey’s mother’s can be infused with guilt, and that possibility should be evaluated and addressed if appropriate.

In closing the discussion Dr. Klein should, irrespective of whether a decision was made regarding Joey’s participation in the experimental treatment regimen, describe a plan that includes an additional consultation, if necessary, as well as any subsequent tasks that need to be completed. All parties should be thanked for their participation and contributions, and a note summary should be made in the Joey’s health record. Dr. Burnet should be recognized because, while many physicians have knowledge and experience in several areas touched by this case, patient care really benefits when one acknowledges one’s own limits and utilizes local resources available. This is undoubtedly a difficult case that involves the management of multiple parties, exploring their interests, and an effective command of several highly complicated and still developing ethical topics.

References

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