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Joey Knows Best? Balancing Conflicts and Defending a Child's Best Interest in Difficult Clinical Decisions

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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

Joey’s story presents the difficult situation of a child facing a life-threatening illness and potentially harmful treatment. Decision making for children is significantly more complex than in adult cases as minors are not deemed capable of deciding for themselves, raising the question of how to weigh childrens’ and parents’ preferences. Joey’s situation is all the more complicated because his parents disagree with each other. Dr. Burnet did well to recognize the complicated nature of this case and the necessity to parse out the ethical questions involved. In his discussion with the family, Dr. Klein will need to combine the Belmont report’s primary bioethics principles (nonmaleficence/beneficence, respect for persons, justice) with an analytic framework that reflects the particularities of pediatric clinical decision making [1, 2].

Research Participation as a Treatment Option

Because the experimental offered to Joey is part of a research study, concerns specific to research (as opposed to routine clinical care) must be addressed. We may conclude from the vignette that the family is adequately informed of the potential benefits and harms of the study and alternative options and that Dr. Burnet has no conflict of interest. This does not mean that Dr. Burnet is an impartial actor in the discussion regarding Joey’s treatment: his duty is to advocate for Joey’s best interests. Secondly, we must make sure that Joey and his family understand the distinction between treatment and research. The therapeutic misconception, the mistaken perception that treatments being researched are intended for therapeutic benefit, is common among participants in clinical research, and patients faced with life-threatening illnesses are particularly vulnerable due to their desperation for any chance to prolong life and well-being; this is especially true in pediatric oncology, where the lines between clinical care and research are often blurred [3].³ Dr. Klein must ensure that the family understands that the purpose of the study is to compare the experimental treatment to traditional treatment, and that it is unclear whether the experimental treatment is superior—in fact, it may lead to a much worse outcome if the reduced radiation dose causes higher mortality and does not prevent side effects as hypothesized. Finally, it must be made clear to Joey’s family that they can discontinue their participation in the study whenever they wish.

Does Joey’s Opinion Count?

The first question that Dr. Klein must address is whether and how much Joey’s opinion matters—that is, the question of Joey’s autonomy. In assessing the value of a minor’s treatment preferences, one must take into account maturity and decisional capacity [4]. Clearly, a 3-year-old would not be fit to choose her radiation treatment

but we might afford a 17-year-old nearly as much decisional authority as an adult. What of children who, like Joey, are “in the middle”? Based on studies of cognitive development, some authors and institutions have advocated thresholds of 7 or 14 years of age to involve children in clinical decisions by obtaining their assent [5, 6]. However, the use of a threshold seems exceedingly arbitrary. A gradualist and individualist approach, which recognizes that the development of decisional capacity is a gradual rather than discrete process and that individual children progress differently toward maturity is more likely to result in a fair assessment of each case.

Joey seems an intelligent and mature 12-year-old; and indeed, the experience of serious illness can make children “grow up” faster than their age peers [7]. Joey has demonstrated his understanding of his treatment options and potential consequences, and an ability to manipulate these facts and his own values to arrive at a decision, thus meeting commonly used criteria for decisional capacity [8]. Moreover, because children generally have a tendency to go along with their parents’ decision (less so as they mature), Joey’s openly voiced disagreement indicates a capacity for independent judgment and the fervor of his desire to participate in the study [9, 10].

The nature of Joey’s illness also affects the value of his preference. Children in end-of-life situations may be given more say in deciding between life-extending measures and comfort care that optimizes quality of life, reflecting an understanding that, the more life-altering the situation, the more difficult it is for a surrogate decision maker to comprehend the patient’s experience and the tradeoff involved in the decision [11, 12]. Although Joey is not necessarily in an end-of-life situation, he has a life-threatening illness and faces the risk of significant decrease in quality of life. Given his demonstrated level of maturity and his illness, Joey’s preferences must be taken in serious consideration. However, this does not imply that Joey’s position should be adopted unequivocally. Certainly, legal statutes require that Joey’s parent(s) approve and, ethically speaking, the gradualist approach mentioned above allows us to recognize that, although Joey’s opinion matters, we cannot consider him to have full decisional autonomy as we would an adult or older adolescent.

Can Parents Decide for Their Children?

Parents, as the primary caretakers, are generally assumed to be best suited to decide in children’s stead. For adults, surrogate decision-making relies on the notion of substituted judgment; that is, a surrogate decision-maker is expected to make the choice that best represents the patient’s own judgment [13].¹³ Thus, for adults, it is crucially important *who* decides, as this person must be familiar with, and able to honor the patient’s preferences. However, in pediatrics, substituted judgment is not truly applicable, as parents’ decisions cannot be deemed to reflect the judgment that their children would make if they had full decisional capacity [13]. Although children often eventually adopt values similar to their parents’, it is impossible to know what Joey would have decided as a fully autonomous adult. Parents’ choices reflect their values and, often, their own interests [14]. This may lead to a conflict when, for example, a parent opts to forego extreme life-saving measures for a child

who could have survived, but with significant neurologic deficits, because the burden of caring for the child would be too onerous. Although it is clear from her emotional distress that Joey's mother wants the best for him, she also has an interest in protecting herself from the immense grief of losing one's child. Thus, because parental decision making is not equivalent to true *consent*, it may be more accurate to refer to parental *permission* [12]. In our case, both parental permission and Joey's assent are necessary.

One consequence of the ethical inferiority of parental permission to true consent is that the question of *who* decides is less relevant than the question of which decision upholds the child's *best interests* [13]. In Joey's case, an attempt to choose an appropriate decision maker would lead to a dead end. Joey's mother may be considered better suited than his father to decide as she is the custodial parent and may know him better, but Joey's father is very involved in his life and thus his preferences cannot *a priori* be discounted. Because the permission of only one parent is typically required for studies in which the participants may benefit, Dr. Burnet could conceivably enroll Joey with just the father's consent.¹² However, Dr. Burnet rightfully recognized that this would have been an unwise and unethical decision in its disregard for the mother's concerns and the risk of discord within the family. It is clearly in Joey's best interest that consensus be achieved and the integrity of the family relationships be maintained.

In sum, Dr. Klein's task rests in determining whether Joey's interests are best served by "vetoing" his treatment preference or abiding by it. Dr. Klein will have to have the family identify and weigh the potential benefits and harms of each option to determine which best upholds the principles of beneficence and nonmaleficence.

Determining Joey's Best Interests: Harms vs. Benefits

A comprehensive and systematic analysis of harms and benefits must encompass the magnitude and likelihood of both direct and indirect consequences, including physical, psychological, social, and economic outcomes. Here, knowledge about the clinical (physical) outcomes of the two treatment options is insufficient to make a definite determination; while some clinical decisions have a clear answer regarding the child's best interest (e.g., protection of a vaccine vs. transient pain of the injection), there is no such easy answer to the tradeoff between potentially decreased chance of survival and potential (but not guaranteed!) protection from neurocognitive side effects.

However, the psychological and social impacts of each option do offer valuable insight. First, regardless of the final decision, there is a risk of discord between Joey's parents and consequent psychosocial stress for Joey. If Joey is allowed to participate in the study, the mother may feel slighted that her opinion was not respected. On the other hand, the father might feel slighted if Joey is not allowed to participate. Because the risk of parental discord exists with both decisions and can reasonably be assumed to be equally likely, it does not enlighten our decision

process. (Nevertheless, mitigation through counseling support throughout the treatment process is essential.)

If Joey were not allowed to participate in the study, he is likely to develop resentment towards his parents (especially his mother) and the treatment team, with potential consequences including decreased engagement in the treatment plan (and poorer compliance) and a long-term rift in his relationship with his parents. If Joey does develop cognitive impairment, he will also bear the pain of living with a disability that he had explicitly sought to avoid, an added psychological cost on top of the burden of the cognitive impairment itself. On the other hand, allowing Joey to enter the study presents the potential benefit of validating his developing sense of autonomy. Of course, if the experimental treatment were unsuccessful, this could result in tremendous guilt on the parents' part for opting for the less certain treatment, but in weighing Joey's best interests the parents' guilt matters primarily insofar as it affects Joey, which would not be the case here.

With no further factual details, this analysis indicates that, taking into account potential psychosocial outcomes, and given the lack of a clearly clinically superior option, the best decision is to respect Joey's preference and allow him to enter the study. One test of the robustness of this decision framework is to apply it to the converse situation, that is, if Joey did not want to participate in the study but his mother wanted him to. Here again, assuming similar potential clinical outcomes, the psychosocial consequences of deciding against Joey's desires would weigh most heavily and guide us towards respecting Joey's decision. Of course, parental permission remains paramount—our conclusion serves only in making recommendations to the family as to the *decision process* rather than the actual *treatment*.

Conclusions

Dr. Klein faces the delicate task of guiding a family facing a very difficult clinical decision for a pre-adolescent child with a life-threatening illness. In discussing the family's options, Dr. Klein must be empathetic to the deeply emotional nature of the situation and to each family member's viewpoint, acknowledging the valid reasons for each preference. Joey and his parents should be given sufficient time to reflect upon their decision (albeit with consideration for the need for prompt treatment to optimize outcomes). In seeking consensus, Dr. Klein must emphasize the importance of Joey's level of decisional capacity and his understanding of the choice he faces. He should then walk the family through the potential benefits and harms outlined above and elicit any additional concerns and the family's own assessment of the magnitude and likelihood of these potential outcomes. It is crucial that the ethical analysis take into account the family's unique circumstances in order to properly weigh the potential benefits and harms and arrive to the right conclusion for this specific family. Nevertheless, the steps above offer a systematic, comprehensive, and robust approach to achieving a decision process that puts the entire family at ease and allows them to face Joey's illness as a united front.

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