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Pediatric Forum

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Her Own Decision: Impairment and Authenticity in Adolescence

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INTRODUCTION

Welcome to the first *JCE* Pediatric Forum, in which members of the American Society for Bioethics and Humanities (ASBH) Pediatric Ethics Affinity Group (PEAG) present challenging pediatric ethics cases with analysis from multiple perspectives. Readers are invited to submit their challenging pediatric cases to Sabrina Derrington, MD, at sderrington@chla.usc.edu.

ABSTRACT

This case describes an adolescent in a crisis of a chronic medical condition whose situation is complicated by substance abuse and mental illness.

D. Micah Hester provides an analytic approach, teasing apart the multiple layers of medical, developmental, and

moral issues at hand and describing possible responses and outcomes. Amy T. Campbell examines existing legal guidelines for adolescent decision making, arguing that greater space exists for clinical discretion in these matters than commonly thought. Cheryl D. Lew discusses the development of agency in adolescent patients, the ideal of autonomous decision making in the context of impairment and chronic illness, and the obligation of healthcare teams to examine an adolescent patient's decisions in relation to her identity.

CASE PRESENTATION

C.M., a 17-year-old female, presents to the emergency room two years after having received a cadaveric kidney transplant. She has missed several clinic appointments in the months prior, and labs on admission show evidence of significant rejection. She is admitted with a plan for intensive anti-rejection treatment with intravenous infusions of chemo-

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therapy. On further questioning from the transplant team, C.M. admits poor compliance with her medications—"I just forget sometimes." The social worker on the team notes that C.M.'s grandmother, her only guardian, is battling breast cancer and has been recently hospitalized, and suggests a psychiatry consultation to assess for depression. The child psychiatrist evaluates C.M. and immediately notes her flat affect and indifferent attitude. During their conversation, C.M. says she has been using crystal meth regularly and that it's the only thing that makes her feel good.

When asked if she is scared about kidney rejection and the treatment her doctors are planning, she says she doesn't want treatment, doesn't care that without it she will likely lose her kidney, and it "doesn't matter" if she dies. She denies suicidal ideation. Although the psychiatrist is deeply concerned, he does not feel that C.M. meets criteria for an involuntary hold. He tells C.M. he will ask her transplant doctors to talk more with her about her disease and treatment options, and asks the social worker to contact her grandmother.

CLINICAL ETHICS PERSPECTIVE

D. Micah Hester

The case presents numerous concerns and issues with which medical personnel, the patient, and her family must contend. While not an exhaustive list and using completely artificial categories for organization, some of these issues might be characterized thusly:

Medical layers

- Adherence to medical regimens
- Addiction to illicit drugs
- Possible depression

Developmental/social layers

- Teenage maturity
- Chronic illness
- Grandmother as guardian and with breast cancer

Moral layers

- Teenage decision-making authority
- Refusal by a minor of efficacious treatment
- Responsibilities for stewardship of scarce resources
- Distributive justice concerns

Again, this list is not exhaustive, and surely neither the categories nor the issues themselves are mutually exclusive. The physiological, de-

velopmental, and moral are all of a piece in healthcare, and teasing them out, while a useful exercise to help get a handle on the complexity of the situation, must be done in a way that is careful not to ignore the lived experience of those involved, for whom the medical encounter is not simply about one's body but about one's life. For example, it would seem important to evaluate the patient's status as a decision maker in light of her nonadherence, addiction, and possible depression. The morally laden practice of determining whether a minor should be given decisional authority ought to be informed by her developing cognitive abilities, her personal experiences, as well as the extraneous forces of relationships, drug use, and even personal self-esteem. Surely, given both the concern about her future health/living and the scarcity of the resource in question (a working kidney), the moral tensions are significant and the stakes quite high.

Others in this section will argue bioethical/legal concerns. The point of this section is to provide a simple analysis that delimits the possible responses and outcomes, regardless of the moral and legal approaches taken. To that end, it would seem that there are only limited responses that healthcare personnel can make at this time, including:

1. Taking time for further investigation of the cause of C.M.'s adherence issues and possible depression in hopes of finding ways to change her lifestyle, habits, and decisions with regard to her health and well-being;
2. Finding some way to involve her grandmother in discussions since she has legal standing in regards to medical decision making for this patient;
3. Establishing the need for another legally authorized decision maker (other family member).

While listed separately, again, these need not be mutually exclusive. Taking them in turn, though, #1 implies, in part, the belief that the patient's participation is necessary to successful medical treatment and avoidance of rejection. Of course, this is not unique to our case. Frankly, to the extent possible, all patients

should be participants in their own healthcare. Further, though, #1 may also (but logically need not) lead to belief that the patient, even at 17, is the rightful medical decision maker. More will be discussed later on this, but it is not new to point out that any preset age of “majority” is, at best, contingent and often arbitrary. Some patients who are under 18 surely do have the maturity, development, and experience to handle even challenging healthcare decisions for themselves. The difficulty is determining, especially in complex cases like this one, whether the patient in front of you truly has the decisional capacity to warrant giving her such authority.

The second option recognizes that someone else may have authoritative moral and legal standing with regard to the medical decisions to be made—often a parent, but not always. So, option #2 begins with the recognition of the grandmother’s role, since, in the absence of a parent or other adult family members, a grandparent is typically granted decisional authority over a minor. And yet, even if she is able to perform the role, the second option may or may not lead to the grandmother as the determinative authority for decision making. It is possible that, through this process, it is determined that the patient or someone else should have decisional authority. It is that “someone else” who is mentioned in option #3.

Option #3, then, implies that neither the patient nor the grandmother is in a position to have the final say. In fact, given the grandmother’s condition and the patient’s many considerations, it is a real possibility that decision making would best be handled by someone else—for example, a guardian *ad litem*. Of course, this recognition, if it comes at all, should only come at the end of long conversations with the patient and grandmother that lead to a determination to find someone else to make the call. In this way, the process recognizes the importance of the patient’s participation, but only to the extent possible for the patient (and her family).

Finally, it would seem that whichever of the three options is ultimately pursued, the outcomes are but four:

a. The patient accepts treatment and maintains adherence to the medical regimen;

- b. The patient accepts treatment, but later fails adherence;
- c. The patient continues to reject treatment, and avenues are pursued (be they through established decision makers or the court) that would (could) lead to forced treatment;
- d. The patient continues to reject treatment and so is provided comfort measures leading to full-on rejection and death.

A fifth outcome (e) might be formulated thusly: the situation remains unresolved. Of course, life ultimately does not, in fact, afford us this option. Long-term, option (e) necessarily resolves into (d), minus the more controlled practices implied—namely, intentionally providing comfort measures to ease death.

As noted above, the point of all this is to set out what is at issue and what is at stake in this case. While the issues here are complicated, the possible endpoints are finite. The moral considerations regarding decisional authority, stewardship, protection, and participation require evaluation in light of the practical realities that maturity, nonadherence, addiction, rejection, and possible death delimit in this case.

LEGAL PERSPECTIVE

Amy T. Campbell

When approached from a legal perspective, this case presents questions regarding who can make treatment decisions, and how. In general, the law sets an age of majority, after which persons are legally adult and presumed competent to consent for their own healthcare. The age of majority is a state-by-state legal demarcation, with most states setting the age at 18 years (none less than 18).¹ In our case, the 17-year-old patient is thus a “minor,” and hence legally incompetent to make healthcare decisions, leaving authority with her parent or legal guardian. While these bright-line rules provide guidance, they do not control all adolescent treatment decisions.

The law allows minors to make their own decisions under certain conditions or for certain services.² The latter are typically services

like prevention and testing for sexually transmitted disease, family planning, pregnancy-related care, or mental health services.³ The goal is to incentivize help-seeking behavior and also to protect the public's health. Other conditions that could change decision-making "status" include designating the teen as emancipated or deeming her sufficiently mature to make certain decisions.⁴ Common statutory emancipation "triggering events" include marriage, parenthood, military service, or living on one's own and being financially independent.⁵ The latter scenario (financial independence/living on one's own) may be the case with our patient; it would be important to tease out more of the context and relevant state laws to see if she may in fact be considered emancipated and hence able to consent (or refuse) treatment on her own. (This does not address whether she has adequate capacity to make this decision, but rather creates legal space for her to do so.)

Alternatively, it may be determined that an adolescent has sufficient maturity, as developmentally and contextually understood, to make certain decisions, or at the very least to take on a shared decision-making role. If it is determined that our patient is sufficiently mature to consent, clinicians must obtain her informed consent to treatment; alternatively, this would also give her some rights of informed refusal.⁶ Developmental considerations, especially vis-à-vis her maturity to make treatment refusals with significant consequences, may caution against placing with her the full right to decide the course of treatment. But were she to be legally given the right to consent (or refuse) treatment, then the considerations against the exercise of her rights would, as with an adult, necessitate serious evaluation of her capacity to make decisions (rather than depending on her being a minor and hence "incompetent" to make any decisions, that is, a bright-line rule).⁷

When considering her maturity to independently make or be a partner in making treatment decisions, as with all patients, the law will expect some sort of capacity assessment. Much is left to clinical discretion, a legal recognition of the developmental, highly case-sensitive nature of these decisions. With adolescents, as with

other patients, capacity assessment evaluates whether she:

- Understands the nature of her prognosis and treatment options,
- Appreciates the consequences of her decision,
- Can reason through available options, and
- Can communicate a *voluntary* choice.⁸

Capacity assessment should not be used by clinicians to challenge decisions with which they disagree.⁹ With adolescents, however, the law may allow for a slightly more paternalistic approach to benefit the patient, inasmuch as adolescence is marked as a period of boundary testing and "snap" judgments that may not reflect a fully competent patient's wishes. Our patient also evidences signs of depression and substance abuse, which may impair her capacity to make decisions. While a simple diagnosis does not render her automatically incapable, the totality of evidence, coupled with a diagnosis, may suggest solid reasons to question her capacity, at least for certain decisions at this time (that is, still a minor, depressed, and using drugs). The law then would allow "space" for clinical discretion to consider her maturity in light of the weight and complexity of the decision at hand, that is, to consent to aggressive chemotherapy and potentially prolonged hospitalization or to allow her to reject her kidney completely, leading either to dialysis and re-transplantation (yet another decision) or death.

So let's suppose C.M. is not emancipated, not sufficiently mature, and/or incapable of making her own decisions: who would be her surrogate decision maker? Such a weighty decision necessitates that the grandmother's legal guardianship be confirmed. If she is indeed the legal surrogate, she is expected to make decisions based on the best interest of the patient.¹⁰

Finally, if the decision is to treat over the patient's objection, the law and ethics require solid evidence to justify this decision. This would include discussion with the surrogate decision maker, capacity assessment, and clinical determination of the patient's maturity. This patient is almost at the age of majority; continuing treatment despite her objection will soon

become not only practically but legally difficult. There must be a clear recording of why the team went ahead without her consent—or assent—as well as a thoughtful plan for her transition to adulthood. Given the difficulties in forcing treatment and maintaining compliance, the limited nature of the “resources” (organs), and her closeness to an age of majority—however developmentally arbitrary such an age might seem—this author believes the patient would likely be allowed to refuse re-transplantation.

The reality may be that the scarcity of organs and fears of how “good” a candidate she might be would drive (even subconsciously) the transplant team’s approach; too, it may be that those who would argue for treatment over C.M.’s refusal see, in her grandmother, a surrogate who would “side” with them (leading to a decision around incapacity). A more honest, respectful, and legally thoughtful approach would deal with these motivating factors, through sharing with the patient concerns over her treatment, what’s involved, what consequences emanate from her decisions, how current decisions may connect—or not—from her earlier decisions, the value in having supports in making decisions, et cetera. Shared decision making in this situation, this author would argue, should allow for dialogue with C.M. and her grandmother—to the extent that her grandmother can be involved and the patient can be encouraged to open up to supports in decision making. This approach would recognize the value that many of us place in support systems, especially for adolescents who are developing and testing abilities to define self and to recognize the strengths and limitations of medicine in helping achieve a “healthy” self. For C.M., this may require a bit of time (to the extent there is any) for drug treatment and/or counseling to ensure her capacity is strengthened as much as possible.

In sum, the law is a rather blunt instrument when it is invoked in clinical dilemmas such as this case. It is this author’s belief that key stakeholders often hide behind “the law” to explain constraints on decision making that may not, in fact, exist. It is outside the scope of this article to argue if this is more the law or the clinician’s “fault,” or how such situations might

be generally remedied. For our purposes, suffice it to say that the law often does not say what some think it does (for example, “must” treat adolescents when life is at stake); nor does it always apply in situations where some may believe it does. Rather, the law often crafts space for context-sensitive—and, for adolescents, developmentally sensitive—decision making. It sets up certain expectations and may set boundaries within which decisions are to be made; within those boundaries, as applied in our case, clinicians have discretion in how they approach the “mature” (or potentially mature, or maturing) minor. This said, in applying that discretion, clinicians must look to other tools beyond the law to assess and identify the “authentic” self’s decisions. To these issues we now turn.

DEVELOPMENTAL/ PHILOSOPHICAL PERSPECTIVE

Cheryl D. Lew

Pediatric healthcare professionals and their patients are fortunate to be seldom embroiled in the kind of situation depicted in the case of C.M. Most commonly, near adult and young adult patients facing serious and chronic medical conditions enjoy the presence and considerable support of families and friends—that is, a complex, involved social network, a “tapesty” of relationships.¹¹ Most frequently if there is moral distress within the clinical encounter, there are “interested parties” or “stakeholders” on all sides and within each group—the healthcare team versus the patient/family unit, and within both the healthcare team and patient/family unit. For most pediatricians, this means at least the possibility and often the necessity of conversation—at first contentious, but then eventually, perhaps, consensus. Clinical ethicists and ethics committees may be helpful to the various stakeholders in identifying the issues and achieving consensus.

Well, those are the typical scenarios in children’s hospitals these days. And such a scenario might have played out with the case of C.M., had there been an adult family member or members available, and also had C.M. appeared to

be willing to engage with the healthcare team. When a patient like C.M., who apparently has no “tapestry”¹² of relationships, comes along, considerable angst and internal conflict arise within each professional—and often among professionals—about what to do, because there may be a perception that there is no “responsible party” who can make decisions on C.M.’s behalf. Even in the absence of a “responsible” adult (here defined as someone age 18 years or older), there would have been the opportunity to converse productively with C.M. had she not seemed to withdraw from that conversation. With both the patient and her family “missing in action” then, the healthcare team members are in a quandary about what their professional obligations are, and to whom those obligations should be directed: to C.M. primarily, to C.M.’s grandmother, to that pervasive but ambiguous entity known as our “society.” What about the issue of her being less than the “legal age” of self-determination? Would it have been appropriate to seek court supervision immediately? Or, how much prerogative ought to be given to a “near adult” patient? Is it justified to allow a 17-and-one-half-year-old complete liberty to decide her own health future? Should the legal thresholds described by Amy Campbell, above, be administered strictly and without exception?

Is personal autonomy a capability that only becomes valid on one’s 18th birthday? I would submit that it is not, and that a far more nuanced understanding of the place of autonomy, as well as its relationship to agency in the transition from childhood to adulthood, could allow healthcare professionals to evaluate more effectively the changing agency of their troubled adolescent patients.

The ideal exercise of autonomy requires decisions and actions on one’s own behalf that reflect deeply held internal values and personal life goals that are consistent over time. The persistence and consistency of personal values and life goals over time contribute to the notion of the authenticity of an individual’s pattern of decision making.¹³

This autonomous ideal in mind, why do adolescents make the decisions they do? There is considerable recent work on this phenom-

enon, particularly in the context of “risk-taking” behaviors.¹⁴ The common view among healthcare providers is that adolescents exhibit cognitive analytical capacity, but without the “emotional” maturity to temper decision making. Therefore, the usual conclusion is that adolescents do not make good decisions about their own healthcare. However, there are ample older observations supporting the notion that adolescents experiencing chronic and severe life-threatening illness develop insight and ability to make self-determination decisions similar to that of adults.¹⁵ Therefore, we could surmise the possibility that our 17-year-old has developed morally recognizable decisional capacity before she has made the formal legal transition into adulthood—a matter of a few months. It follows then that one could expect C.M. to have developed some different insight into the “burden” of her chronic illness, and the “burden” of the treatment that is not shared by the members of the healthcare team, or even her remaining family member, thus giving her a greater claim to the prerogative of either accepting or foregoing present and future treatment.

C.M. has seemingly demonstrated behaviors and decisions about her healthcare and lifestyle that are counter to her own best interest for a high quality of life in the future. Should the adolescent whose decision(s) appear to be in conflict with her own best interest be afforded more or less prerogative? In a recent debate about whether late adolescents ought to be allowed to forego life-sustaining, if not curative, medical treatment, Lainie Friedman Ross argued that adolescents’ refusals of treatment for life-threatening illnesses (even when parents support the refusal) ought to be overridden when the proposed treatment is highly efficacious, in order to avoid foreclosing the opportunity for the future adult to exercise her full and mature capacities for “reasoned” decision making.¹⁶ Ross does not address the condition of a reasonably (but not highly) efficacious treatment like renal transplantation, which carries a significant maintenance burden. Accepting a transplanted organ is not curative, but rather is a trading of the disease of chronic renal failure for the disease of transplant recipient. In C.M.’s

case, there is no parent present to either support or challenge C.M.'s *de facto* foregoing of "life-sustaining treatment." Does that matter? If the dying grandmother had been present or had made clear in some way her views about how her granddaughter's treatment should proceed, would the healthcare team have felt obliged to give greater weight to the grandmother's opinion if it conflicted with that of C.M.?

Perhaps the pathway of conceptual "least resistance" for the healthcare team in dealing with our 17-year-old young woman is to assume that she is simply behaving as an "irresponsible" drug-addicted teenager and enforce compliance through legal means with medical treatment for her chronic renal failure: aggressive management of organ rejection, resumption of dialysis if necessary, a strict dietary and medication regimen, and establishment of family court jurisdiction given the grandmother's own health crisis. I say *conceptual*, because actual implementation of such control over a 17-year-old who retains any ability to resist is a fruitless exercise. The behavior of very much younger children can, in practical terms, be constrained in ways that are not feasible for adolescents, short of imprisonment or heavy sedation.

An alternative and more satisfactory approach for the healthcare team would be to examine the young woman's greater social context; that is, who she is, and who her grandmother is, in terms of other family, social relationship, socioeconomic class, ethnicity, and cultural contexts. What might have changed, aside from the grandmother's cancer, over the years of treatment for chronic renal failure? A richer narrative might allow construction of a truer picture of her person and her identity and provide a rationale for her actions and decisions.¹⁷ Hilde Lindemann has been concerned with a concept she calls "holding someone in her identity," in which, only by developing a person's comprehensive biography, can we make sense of her or his outward expression of personal values and desired destiny.¹⁸ Further, Lindemann holds that how we view an individual may either allow that individual full use of her or his identity, that is, if we view her or him to be fully capable of exercising her or his

own autonomy, or may give us license, even subliminally, to constrain that autonomy.¹⁹

This young woman was deemed an appropriate candidate to receive a new kidney two years previously. Although she was only 15 years old at the time, transplant teams commonly place great weight on the commitment of adolescents to making the transplant experience work. So, one can assume that she had an active role in qualifying to be an organ recipient. Let's say she assented for renal transplantation out of consideration for the feelings of her grandmother. Decisions made by adult individuals, and adolescents, may have more to do with respecting the desires of their loved ones than with satisfying their own personal wishes.²⁰ If we "hold her in her identity," that is, presume that C.M. is the same person she was two years earlier, then we are obliged to believe that her current actions derive from the same core identity. Short of credible evidence that she has "lost her mind," we must take as authentic her current assertion that she no longer desires to continue with her transplantation illness, nor even to continue with aggressive management of her chronic renal failure (when her transplant fails completely). What if, now that her only significant family member is soon to die, the young woman feels free to refuse further life-sustaining treatment on her own behalf? She has lived with chronic renal failure, knows its burdens, and now knows the burdens of being a transplant recipient. Should she not also have the choice of whether or not to continue?

For the adolescent patient who is an identity in growth and transition, it seems particularly important to examine that identity deeply and comprehensively and to allow her to make even "unpopular" decisions. Since we accept decisions for no treatment on behalf of adults in similar circumstances, we certainly ought to confer the same respect to adolescents, if their stories make coherent their actions.

CASE CONCLUSION

Attempts to contact C.M.'s grandmother were unsuccessful that evening. The transplant team consulted the hospital

ethics committee, who planned a full evaluation for the following day. Sadly, sometime early that morning, C.M. ran away. Attempts to contact her were unsuccessful and she was again lost to follow up.

SUMMARY

The number of complex ethical issues involved in this case almost make it seem artificially constructed. Would that it were so; unfortunately, this young woman in all of her complexity and this situation were quite real. Space constrains us from adequately addressing the many facets of this case, but at its heart lies a question about what it means to make authentic decisions—and the amount of latitude our society is willing to give individuals who make decisions we consider to be foolish, self-destructive, or wasteful. Can an adolescent, especially one with a chronic illness, make authentic decisions? Both Amy Campbell and Cheryl Lew have presented evidence that this is often—although not always—the case. What about patients with substance addiction? Ongoing neurobiological research and fervent ethical debates are struggling to define whether addicts can be held responsible for their behavior, or whether addiction restricts autonomy enough to warrant compulsory therapy.²¹ This still-developing field has yet to examine how, or if, addiction affects medical decision making. What about depression? There is some good evidence to suggest that patients with major depression have diminished cognitive functioning in several realms that are important to informed decision making, and the potential impact of depression on our patient's thinking ought to be carefully assessed.²² But as Lew makes clear, determining whether or not C.M. is making an authentic decision can only be done by taking the time to understand her in the context of her life story. This richer narrative would be enhanced by any insight her grandmother could have contributed and complemented by psychiatric and neurocognitive assessment. The challenge for the healthcare team then lies either in accepting C.M.'s choice, despite its tragic consequences, or, if she is found to be truly impaired, in finding appropriate and respectful ways to constrain

her behavior (pragmatically difficult, perhaps impossible) and treat both her medical and psychiatric disease.

Tragically, the time necessary to achieve that level of understanding of C.M. was cut short, leaving us with lingering questions about the motivations prompting her decision to leave. One wonders whether this could have been prevented, whether the healthcare team ought to have been more involved in C.M.'s life after her transplant, or if the psychiatrist ought to have had a higher level of concern that night. Healthcare providers are accustomed to dealing with unwise, self-destructive behavior in adult patients: "There is only so much we can do," they say; "we can't force her to take care of herself." The attitude among pediatric professionals is vastly different, a tangled web formed by obligations to protect and defend on the part of both the parent/guardian and the healthcare provider. What pediatricians (and parents) must remember, however, is that most children, even those with chronic medical conditions, grow up and become adults who must make their own lifestyle and healthcare decisions. As a specialty, transitional medicine is still in its infancy, but its fundamental tenet is that "transition" begins at the time of diagnosis, by educating and empowering children (in stages appropriate to their development) to understand their disease and care for themselves. This difficult case suggests that a crucial aspect of that process ought to involve exploring and understanding a child's identity as a person, and not only as a pediatric patient.

MASKING OF THE CASE

All of the details in the narrative of C.M. that might identify any person involved have either been removed or altered so that the substance of the issues raised may be presented without infringing privacy or violating confidentiality.

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