Feature

How Should Clinicians Respond When a Parent's Medical Decision Making for their Child Is Influenced by the Parent's Psychotic Illness?

Shannon Barnett, Nadia Zaim, and B. Simone Thompson

ABSTRACT

Parents are presumed to have decision-making capacity and authority to make treatment decisions for their child. Healthcare providers only question parents' capacity and authority when their decisions place their child at imminent risk of death or permanent disability. Presuming parents' capacity respects the autonomy of parents and the family to incorporate their religious and cultural values into the decisions they make for their child's medical care. Yet there are times when a parent lacks decision-making capacity, which hinders them from making autonomous decisions. How should the medical team respond when they suspect that a parent has a condition that impairs their decision-making capacity? Should the medical team allow the parent to continue to make medical decisions as long as there is no imminent risk of death or permanent disability to their child? If a parent's decision presents a risk to their child, should there be a formal protocol to assess the parent's medical decision-making capacity?

In this article, the authors aim to initiate discussion of these issues by summarizing current thinking about parental decision making, presenting two cases of children admitted with psychiatric conditions when the parents presented with psychosis—a condition frequently associated with decreased decision-making capacity—and provide ways that clinicians might approach similar situations. The cases also illustrate the need to acknowledge and address cultural and contextual issues that impact a parent's decisions, even when a parent lacks decision-making capacity.

INTRODUCTION

Children depend on adults to make medical decisions on their behalf until they have developed the cognitive skills required to understand and communicate their own preferences. Parents are the legally designated medical decision makers for their child, in part because parents are presumed to know their child better than anyone else does, and they are assumed to have their child's best interests at heart.[1] This

---

Shannon Barnett MD, MBE, is an Assistant Professor in the Division of Child and Adolescent Psychiatry at the Johns Hopkins School of Medicine in Baltimore, Maryland. *sbarnett @jhmi.edu*
Nadia Zaim, MD, is a Assistant Professor in the Division of Child and Adolescent Psychiatry at the Johns Hopkins School of Medicine.
B. Simone Thompson, LCSW-C, is a member of the Johns Hopkins Hospital Child Protection Team at the Johns Hopkins Childrens' Center in Baltimore.

is known as the "best interest standard": when a capacitated person is assigned the authority to make decisions for another, based on what the capacitated person understands to be in the other person's best interest.

Because children have interests that are separate from those of their parents, parents have a moral obligation to make decisions that are in their child's best interest, rather than base their decisions on their political opinions or their mistrust of clinicians.[2]

This moral obligation to act in their child's best interest recognizes the reality that parents must balance what is in their child's best interest with their competing obligations to their other children and to their family unit as a whole. Parents must balance the needs of each family member—adults and minors—to maintain the integrity of their family while they protect their individual child.[3] This balance and the specific decisions parents must make are understood to be the best decision available for their family at that time, even though others might choose differently in similar circumstances.

While parents should make decisions that are in their child's best interest, they are given wide latitude to define what is best. This latitude is necessary for several reasons.[4]

First, it is often impossible to develop a consensus about what is in a child's best interest. This is because some parents may prioritize the value of the safety of the child, others their child's quality of life, and others the academic excellence of an institution or careprovider. There is no one agreed-upon hierarchy of values to dictate which values take priority when parents decide what is in their child's best interest.

Second, as a society, we frequently allow parents to make decisions that are not in the absolute best interest of a child. For example, parents may allow their child to eat unhealthy foods, to exercise infrequently, or to have unhealthy sleep habits.

Third, barriers to a parents' making decisions that are in their child's best interest occur regularly in our society. Parents may have poor relationships with careproviders or be from a marginalized community, which can influence the decisions they make, or decrease their trust in the accuracy of the medical information that is provided to them. Parents may not have the education or the skills in critical thinking, language, or reading that allow them to fully engage in making informed treatment decisions. Parents may have mental illness, a history of trauma, or substance abuse disorders that interfere with their ability to make decisions. In these cases, taking away their decision-making authority may further marginalize their family.

A fourth, final consideration is the potential harm that occurs when a child is removed from parental custody. While it is difficult to separate the effect of removing child from their parents' custody from the factors that led to their being removed, removing a child from their parents appears to have a negative effect on the child.[5] Additionally, the United Nations recognizes that a child has the right to stay with their biological family under most circumstances.[6] Taking all of these factors into account, it is advisable for states to set limits on when to override parents' authority.

The regulations that dictate when a state can limit parents' authority over their child vary, but, in general, parents' authority can be limited when doing so will prevent harm to their child. This is known as the "harm principle," and can be used to take medical decision making away from parents.[7] Under the harm principle, parents are not allowed to make a treatment decision for their child when the following criteria are met:

1. There is a high likelihood of imminent death or serious permanent physical damage if the parents' decision is followed.
2. An intervention proposed by the medical team and rejected by the parents has a good chance of success.
3. The expected side-effects of an intervention proposed by the medical team and rejected by the parents are not as severe as what would be expected if the child did not receive treatment.
4. There are no acceptable treatment alternatives that the parents will accept.[8]

The state intervenes only when all four of these criteria are met. There is a wide gap, therefore, between decisions that use the best interest standard and decisions that meet the threshold for the harm principle.

Acknowledging this difference allows dialog regarding the factors involved in parental decision making, including factors that may interfere with a parent's decision-making capacity.

To further explore these issues, we present two composite cases that involve a child who was admitted for a psychiatric condition and a parent who suffered with psychosis. People with psychosis have often been found to lack the capacity to make medical decisions.[9] In both of these cases, there was evidence that the parent's psychosis impaired their capacity to engage in informed consent for their child's treatment. (The cases have been changed considerably to protect anonymity.) The cases demonstrate that multiple factors, beyond mental health, can combine in a way that impact a parent's capacity to make decisions. In both cases, the parents made decisions that did not meet the threshold for state intervention that would be consistent with the harm principle, and thus the parents maintained their legal decision-making authority without the need to demonstrate their lack of capacity to make a decision for their child.

While assignment of legal authority over their child does not infer that a parent has medical decision-making capacity, in practice, the state does not question a parent's capacity as long as the parent's decision does not meet threshold for state intervention. (Conversely, taking away a parent's decision-making authority does not infer the parent does not have capacity. It just means the parent has made a decision that the state deems unacceptable.) While the parents' legal authority to make treatment decisions for their child was not challenged in either of these cases, the treatment team were concerned that psychosis influenced the decision-making capacity of both parents.

While parents should make decisions that are in their child's best interest, they are given wide latitude to define what is best.

CASE 1

AJ was a 15-year-old Black female who presented for emergency medical care, stating that government agents had implanted a device in her head to control her thoughts. Admission to the psychiatric unit was recommended for treatment of her acute psychosis. This frustrated AJ's mother, who didn't trust the medical team and requested surgical removal of the implanted device. AJ's mother's distrust of the recommendations made by the medical team was complicated by her social history. The city the family lived in was known for government corruption and police violence towards Black citizens, and the hospital had a reputation in the community for discrimination in its care for Black patients.

AJ was voluntarily admitted to the psychiatric unit despite her mother's initial misgivings. She was started on risperidone, but after a few days developed a fever and muscle stiffness. Lab tests confirmed neuroleptic malignant syndrome (NMS), and AJ was transferred to an intensive care unit. When AJ recovered, her mother requested discharge home rather than readmission to a psychiatric unit. Her mother expressed frustration that AJ's initial medical concern about an implanted device in her head was not addressed, and she correctly observed that during the hospital course AJ's condition had worsened. Her mother only signed consent for readmission to the psychiatry unit after a local child welfare agency became involved.

AJ remained delusional and disorganized and was started on a new antipsychotic. Her mother initially consented to this new medication, but later refused to consent to a recommended dose increase. AJ's mother questioned the need for more medication, reminding the team of AJ's decline after the risperidone. AJ's mother also repeatedly asked for a neurosurgical consult and brain imaging to locate and remove the device implanted in AJ's head.

AJ's mother visited the unit for several hours every day. She was attentive to AJ, who was obviously comforted by her presence. AJ gradually became less disorganized and agitated, although she continued to have paranoid thinking. The team continued to recommend increased medication dosage, but her mother insisted that she be discharged. Because AJ's mother consistently believed that AJ had a device implanted in her head (even after she was shown proof from brain imaging), the team believed that her mother was delusional herself. Multiple conversations with AJ's mother suggested that her delusions obstructed her ability to understand the risks of AJ's illness and the benefits of continued inpatient treatment.

CASE 2

LC was an 11-year-old male who immigrated to the United States from a predominately Muslim country with his mother at age four. He was admitted to the hospital in the fall of 2017 after several months of escalating auditory and visual hallucinations, bizarre behavior, and refusal to eat because he feared that his food was poisoned.

Due to his age, his bizarre focus on a specific type of monster, and his poor social skills, the team wondered if LC had a developmental delay that predated his psychotic illness. The team requested permission to speak to LC's teacher to better understand his premorbid personality and developmental level. His mother declined to sign a consent for release of information. Despite repeated attempts to counsel LC's mother on the benefits of speaking with LC's teacher, his mother continued to refuse to give her consent. She was never able to express why she would not allow the team to obtain more information.

Multiple conversations with AJ's mother suggested that her delusions obstructed her ability to understand the risks of AJ's illness and the benefits of continued inpatient treatment.

During LC's hospitalization, his mother complained that she suspected that staff were putting poison in LC's food. She often had difficulty expressing her thoughts in a coherent manner. After a week in the hospital, LC's mother said she wanted him discharged, but she would not sign the form required to request his release when it was offered to her. In addition, LC's mother informed the team that she and LC were moving to live with a cousin in another state immediately upon discharge. She declined to provide the name or contact information of the cousin. She reluctantly provided the name of the city where they were moving so that a referral for community-based services could be made.

The team observed that LC's mother was consistently paranoid and that she consistently had disorganized thinking, which led them to conclude that she was psychotic. The team believed that LC's mother's mental illness impacted her capacity to engage with the team, receive information, and participate in informed consent for treatment for her son. In addition, it seemed that her paranoia prevented her from understanding the importance of collaborating with school staff and extended family to better enable the team to understand LC's presentation and to plan for follow-up support.

DISCUSSION

A review of the literature did not reveal any established protocol to evaluate or consider a parent's capacity to make medical decisions for their child. It is likely that no one has established such a protocol because the legal system does not take parental capacity into account when it determines whether a parent can make medical decisions for their child.

A medical team that wants to evaluate a parent's decisional capacity may incorporate those factors that contribute to assessment of an adult's ability to make decisions for themselves, such as the ability to delineate potential risks, benefits, and outcomes of decisions; consider different options; and hold consistent views over time. At present, information about a parent's capacity to make medical decisions can be used by a medical team to minimize its impact on a child, but cannot be used to deny the parent the authority to make medical decisions for their child.

People with psychosis, especially delusions, frequently do not meet criteria for having the capacity to make medical decisions.[10] The parents of these patients were observed to have delusions, and LC's mother also had significant disorganization of her thought process. While the team did not do a formal exam to be able to formulate a diagnosis for either mother, the symptoms of delusions and disorganized thinking were made through observation, and the mental health team felt confident in the assessment that both mothers suffered from a psychotic disorder that included delusions and disorganized thinking.

In both of these cases, the team spent significant time discussing the risks and benefits of interventions with the patients' mothers, and in each case concluded that the mothers were unable to accurately understand the risks and benefits of potential medical interventions. For example, AJ's mother could not verbalize her understanding of the risks involved in not treating AJ's psychosis, and LC's mother could not verbalize her understanding of the benefits of allowing the team to contact LC's school or extended family. Yet neither case met the threshold of the harm principle. Additionally, clinical experience suggests that it is not uncommon for parents to decline high doses of antipsychotic medications (or even refuse an antipsychotic altogether) for their child. The decisions made by the parents of AJ and LC do not necessitate a conclusion that they did not have decision-making capacity.

The ethics consult service was involved in both of these cases and concluded that both mothers were legally allowed to make medical decisions for their child because their decisions did not place their child at imminent risk of serious or permanent disability or death. In both cases, the ethics team stated that as long as decisions do not meet the threshold for the harm principle, parents are presumed to have medical decision-making capacity.

While the team believed that both mothers lacked the capacity to make medical decisions, they also acknowledged that factors such as systemic racism and the current political climate likely contributed to the parents' decisions. These are factors that a team should consider when working with parents.

The mothers of AJ and LC had legitimate reasons to distrust the doctors at the hospital. There was significant mistrust between the Black community and the hospital where AJ was admitted. In addition, AJ had a life-threatening side-effect to her first antipsychotic trial, and her mother, in questioning the medical team's recommendation, was being an advocate for her daughter.

When LC was admitted, the White House was actively trying to block immigrants such as LC and his mother from entering the United States, and there were efforts to deport anyone from their country who entered the U.S. illegally. It is understandable that LC's mother might mistrust the staff at this American hospital.

POSSIBLE SOLUTIONS

These proposed solutions represent a range of possible interventions. Although not all of them are legal at present, we include them to generate discussion.

Take the Youth into Protective Custody

A hospital could develop a protocol to do formal evaluations of parent's capacity to make medical decisions. If the parent is deemed to lack the capacity to make medical decisions for their child, the state could take custody of the youth and obtain legal guardianship to make these decisions. In assuming the best interest standard, the state could make decisions that would not be affected by psychosis or mistrust of authority.

This approach would allow for medical treatment to be in the best interest of a child, in regard to health, but the cost to the child would most likely be much greater than the benefit. In the two cases we have presented, both youths had a caring relationship with their mother. Both mothers spent time with their child, advocated for their child, and helped with activities of daily living. In addition, both youths experienced acute psychotic episodes, which can be very upsetting. Taking the youths away from a supportive parent could add significant trauma distress to the existing stress of a psychotic illness. Finally, both of the mothers had experience navigating the world while psychotic. They may have a unique perspective and skill set that could help their child as they go through life with a psychotic illness.

Take Away a Parent's Right to Make Medical Decisions

Another option would be to do a formal capacity evaluation on the parent. If the parent lacked the capacity to make competent medical decisions, the state could appoint a guardian to make medical decisions and allow the youth to stay under their parent's care. This would allow decisions to be made without parental interference. There would be a high risk, however, that this action could increase a family's distrust of doctors and those in authority. Ultimately it is the family who ensures ongoing care, such as encouraging a youth to take medication and attend appointments. If the state strips a parent of their decision-making role, a likely result may be creation of barriers in the treatment team's ability to engage with the family and influence their behavior.

Allow a Parent to Continue to Make Decisions, But Provide a Patient Advocate

A patient advocate would not have the ability to consent to treatment, but could ensure that a parent who lacks capacity to make competent decisions would not consent to a treatment that was not in the child's best interest. For AJ, an advocate could provide an outside point of view in balancing the risks and benefits of restarting an antipsychotic after an episode of NMS. For LC, an advocate could help the team decide whether to accept his mother's verbal request for his discharge.

Allow a Parent to Continue to Make Decisions, Without Other Interventions

This is the current standard. When a parent has decision-making capacity, this is the approach that maximizes the autonomy of parents and families. Unfortunately, when a parent lacks decision-making capacity, there is a risk that outside influences could negatively influence their decisions. For AJ, we do not know whether her mother would choose an antipsychotic trial if her decisions were not influenced by psychosis. Similarly, we do not know whether LC's mother would allow the team to contact his school and other family members if she was not psychotic. In both cases, these parents may not have made decisions that were in the best interest of their child.

As this approach would be consistent with most current practice, it is important to consider ways to improve clinical outcomes through improving the relationship between the clinical team and the parent. We now outline suggestions below.

OTHER RECOMMENDATIONS

In any clinical interaction, clinicians should optimize their relationship with parents. A good relationship that promotes the dignity of parents by including validation and respect has been found to lead to decreased conflict.[11]

Validation

The mothers of both of these children had legitimate reasons to distrust healthcare workers and people in authority. Racial, economic, and cultural issues likely had a negative influence on the health of both the children and their mothers in the two cases.[12] It is important for those who work with families to be aware of important contextual concerns and to not dismiss such concerns just because a parent has limited decision-making capacity. Healthcare workers should be aware of the legitimate reasons that families may mistrust healthcare systems. Instead of becoming defensive or dismissive, healthcare workers can allow families the space to talk about their previous experiences and can validate that certain demographic characteristics have been associated with poorer health outcomes.

Respect the Relationship

The mothers in these cases were very vulnerable. Offering them praise and support for their engagement at the bedside as they cared for their children could have increased their sense of competence. The staff could have helped them by respecting them as survivors of difficult circumstances who faced the overwhelming task of raising a youth with a major psychotic illness.

Find Common Ground

Staff can work with parents to learn what the parents believe would be most helpful to their child. For example, LC's mother wanted him to go straight from being dismissed from the inpatient unit of the hospital to the local bus terminal. The team worked with LC to develop a list of activities to keep him occupied on the long bus ride to this cousin's home and provided him with a few games and art projects. This reduced his anxiety and was seen by his mother as a show of respect for her decision to move her family.

Healthcare workers should be aware of the legitimate reasons that families can mistrust healthcare systems.

Encourage a Parent to Take Time to Understand All of the Issues

Studies suggest that people who have diminished capacity due to psychosis often make medical decisions quickly, before they learn all of the relevant information.[13] Preliminary data suggest that a brief intervention to help people slow down and consider all of the relevant information may be helpful.[14]

CONCLUSION

These cases demonstrate that parents can lack decision-making capacity and still have the legal authority to make decisions for their child. In such cases, the clinician's goal should be to consider interventions that minimize the impact of the parent's lack of decision-making capacity. By acknowledging the factors that can impact a parent's decision making, careproviders can actively engage families in dialogue regarding options for diagnosis and treatment. Doing so will better inform the team and family as they determine the youth's best interest. It should help careproviders feel more comfortable with a parent's decisions, even when the decisions do not align with the careproviders' recommendations. They can be assured that allowing a parent flexibility to make decisions is usually in the youth's overall best interest.

NOTES

1. A.L. Katz et al., "Informed consent in decision-making in pediatric practice," *Pediatrics* 138, no. 2 (2016): doi.org/10.1542/peds.2016-1485.

2. R. Pinnock and J. Crosthwaite, "When parents refuse consent to treatment for children and young persons," *Journal of Paediatric Child Health* 41, no. 7 (2005): 369373, doi: 10.1111/j.1440-1754.2005.00643.x; United Nations, "Convention on the Rights of the Child," 1989, *https://treaties. un.org/pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-11&chapter=4&clang=_en.*

3. P. Neild, "Irreconcilable differences: A parent's right to refuse to consent to the medical treatment of a child," *Family & Conciliation Courts Review* 33, no. 3 (1995): 342-60, doi: 10.1111/j.174-1617.1995.tb00376.x.

4. Katz et al., "Informed consent," see note 1 above; D.S. Diekema, "Parental refusals of medical treatment: The harm principle as threshold for state intervention," *Theoretical Medical Bioethics* 25, no. 4 (2004): 243-64, doi: 10.1007/s11017-004-3146-6.

5. J.J. Doyle, Jr., "Causal effects of foster care: An instrumental-variables approach," *Children and Youth Services Review* 35, no. 7 (2013): 1143-51, doi.org/10.1016/j.childyouth.2011.03.014; J. Yang, E. McCuish, and R. Corrado, "Is the Foster Care-Crime Relationship a Consequence of Exposure? Examining Potential Moderating Factors," *Youth Violence and Juvenile Justice* 19, no. 1 (2021): 94-112, doi:10.1177/1541204020939643.

6. United Nations, "Convention," see note 2 above.

7. Diekema, "Parental refusals," see note 4 above.

8. Katz et al., "Informed consent," see note 1 above; Diekema, "Parental refusals," see note 4 above; M. Shapiro, "Pediatric depression: When does parental refusal for treatment constitute medical neglect?" *Journal of the American Academy of Child and Adolescent Psychiatry* 57, no. 6 (2018): 363-5, doi: 10.1016/j.jaac.2018.02.014.

9. R. Cairns et al., "Prevalence and predictors of mental incapacity in psychiatric in-patients," *British Journal of Psychiatry* 187, no. 4 (2005): 379-85, doi:10.1192/bjp.187.4.379.

10. Ibid.; A. Larkin and P. Hutton, "Systematic review and meta-analysis of factors that help or hinder treatment decision-making capacity in psychosis," *British Journal of Psychiatry* 211, no. 4 (2017): 205-15, doi:10.1192/bjp.bp.116.193458.

11. S. Steihaug, P. Gulbrandsen, and A. Werner, "Recognition can leave room for disagreement in the doctor-patient consultation," *Patient Education and Counseling* 86, no. 3 (March 2012): 316-21, doi: 10.1016/j.pec.2011.06.011; J. Schmidt, M. Trappenburg, and E. Tonkens, "Social dignity for marginalized people in public healthcare: An interpretive review and building blocks for a non-ideal theory," *Medicine, Health Care and Philosophy* 24 (2021): 85-97, doi.org/10.1007/s11019-020-09987-8.

12. D.R. Williams, J.A. Lawrence, and B.A. Davis, "Racism and health: Evidence and needed research," *Annual Review of Public Health* 40, no. 1 (2019): 105-25, doi.org/10.1146/annurev-publhealth-040218-043750.

13. Cairns et al., "Prevalence and predictors," see note 10 above.

14. Larken and Hutton, "Systematic review," see note 7 above.