

Advance Directives in Psychiatry: Cultivating Autonomy in Mature Pediatric Patients

Introduction

Sam¹ is a quiet, introspective 16-year-old who spends most of her time painting. She is a talented artist; her work has won local, state, and national competitions and garnered attention from art programs from universities across the state. At age 11, Sam was diagnosed with bipolar disorder. For the past 5 years, her parents have been supportive of her diagnosis and treatment and worked together with her psychiatrist in creating a treatment plan. As Sam is getting close to her senior year of High School, she is stressed about creating a portfolio of her artwork to submit to colleges. She has been relatively stable on her medications but complains that her ability to create is blocked and she often feels "numbed out."² In the past, she has attempted to stop her medications, but only to experience severe side effects. At her latest appointment, she confides in her doctor that she wants to stop her medications for the foreseeable future, as her best artwork is done when she does not feel so blocked off.

Her psychiatrist expresses concern about her going off her medications, given that she has been relatively stable, just for the sake of finishing her portfolio. Sam responds by explaining the research she has done on mental health advance directives. These contracts allow a patient to outline a treatment plan ahead of time and agree to a course of action for when they become incompetent to make decisions for themselves. She expresses her wish to create one of these directives for when she goes off her medications, that she would like not to have any intervention unless she repeatedly verbally expresses a desire to harm herself or others. Her psychiatrist and parents are concerned about Sam going off her medications and derailing her progress, despite the negative side effects she expresses are causing her psychological harm.

¹ This is a hypothetical case study; any overlap to a real patient is coincidental.

² Emotional blunting is a common side effect of medications (Szmulewicz et al. 2016)

Sam's situation highlights the tension in pediatric psychiatry between autonomy, shared decision-making, and the evaluation criteria utilized in psychiatric care. Thus, the first section will explore the concept of capacities in a clinical context, as well as the problematic issue of conceptualizing psychiatric patients as inherently irrational. In the following section, I will parse out the differences between assent and consent, as well as the clinician's role in developing the patient's autonomy. The third section will focus on mental health care advanced directives and how they can be utilized as a tool with pediatric psychiatry patients. I aim to demonstrate that mature adolescent patients should play a significant role in their treatment plans, and their physicians have the duty to assist in developing their patient's autonomy.

Section 1: Agency and Capacities

When considering a patient's cognitive capacities, the typical approach that healthcare clinicians take is to judge the process at which a decision is reached and not its content. Yet, this creates tension in pediatrics, where usually the process is guided by caretakers asserting what is best (Ruhe et al. 2016). Thus, with pediatric patients, Ruhe et al. suggest a "weak procedural capacity" approach, which promotes the child's decision-making abilities by assessing the content of their decision. There is the prevalent notion embedded in these concepts that the notion of capacity is a *status* (Ruhe et al. 2016). A patient (adult or child) must demonstrate the following to be considered to be deemed as possessing capacity:

- (1) the ability to communicate a decision
- (2) understand relevant information,
- (3) appreciate the situation and likely consequences
- (4) reason about treatment options (Ruhe et al. 2016).

If minors fulfill the requisite criteria, it is suggested that they be able to play a part in the decision-making process. Yet, it is noted that this is difficult to discern a child's capacity in a

couple of relevant ways. First, there is the traditional approach to cognitive development built out of Jean Piaget's foundational theory. By this account, children move through four stages of cognitive development, ultimately reaching the ability to reason and think abstractly (on par with adult's capabilities) by early adolescence. Prominent criticisms of the Piaget approach suggest that children's abilities may be underestimated and contextual factors can tremendously affect performance (Ruhe et al., 2016). Thus, age should not be the sole determining factor in assessing a patient's competence; physicians must be cognizant of the nuances in determining a patient's capacity beyond developmental stages.

Further, there are underlying, pervasive issues within psychiatry that can undermine the patient's autonomy. As Ruhe et al. points out, "establishing (in)capacity is not just a descriptive fact, but often involves a normative dimension" (2016). This is coupled with the concept of diagnostic discrimination and the role this may play in treating psychiatric patients. This is the tendency to group together patients based on similar traits and treat these individuals as having the same underlying, causal mechanism that is leading to their symptoms (Tabb 2016). If physicians are treating patients from this generalized approach, they will not be providing the attentive care that these individuals need. These issues amplify the vulnerable position that psychiatry patients are in by undermining their autonomy.

When these concerns are brought into the scope of a minor population, it is evident that pediatric psychiatric patients are in a particularly vulnerable position. Scholars argue that children face a particular kind of epistemic injustice, known as testimonial injustice, wherein children are considered less reliable sources simply because of their age (Burroughs & Tollefson, 2016; Carel & Györffy, 2014). Further, younger patients seeking mental health care "often report feeling that their concerns are invalidated and minimized by healthcare practitioners" (Bergen et

al., 2022). Thus, in the following section, I outline a few obligations that clinicians should uphold in this particular practice in order to minimize these potential harms and foster autonomy in the patient.

Section 2: The Clinician's Role

An important consideration in pediatric care is the distinction between assent and consent to medical treatments, procedures, etc. Consent is restricted to a legal term based on competence (Unguru 2011). In order to consent on behalf of the child, parents/guardians must demonstrate that they have the requisite competency to do so (Unguru 2011). On the other hand, assent focuses on respecting a child's developing capacity, empowering them to play a role in their medical decision-making. There are two notable role constraints that limit a child's ability for autonomous actions. First, an adolescent patient is placed in a passive position with authority figures (parents and clinicians). As noted, parents reserve the authoritative right of consenting to any given treatment, procedure, etc. This leads to the second constraint: the adolescent is vulnerable due to physical, emotional, and financial dependence on caregivers. The relationship between the child, parent, and clinician illustrates the asymmetrical power dynamics in pediatric care. Parents may assert that the decisions concerning their child's health care are theirs to make and exclude the child from the decision-making process.

Given the tension between the patient, family, and provider, there are a few guidelines for pediatric clinicians to follow in this care. Chiefly, the clinician has an obligation to treat the patient as an end in themselves (Attard-Montalto, 2001). When it comes to pediatric patients, this involves a commitment to developing autonomy; chiefly through advocating for shared decision-making and periodically revisiting conversations of inclusion of the patient in the process; especially in cases where parents continually assert their authority (Attard-Montalto, 2001). Further, it has been demonstrated that adolescent patients in long-term individual

psychotherapy enter a relationship with their clinician with a peculiar intensity, wherein the patient may see their clinician as taking on a “parental” role (Green & Stewart 1987). Thus, the clinician is uniquely positioned to educate both the parents and child on conditions, treatment options, and their particular roles and responsibilities. Recent work on fostering autonomy in pediatric psychiatric interactions has demonstrated that when providers validate the patient’s experiences and include them in the decision-making process, it enhances the therapeutic relationship and potentially improves clinical outcomes (Bergen et al., 2022). Affirming the patient’s experiences and concerns, as well as making them a central part of the decision process, not only furthers their autonomy but also assists in minimizing discrimination unique to psychiatric patients. In what follows, I will explore how the use of mental health advanced directives can be a helpful tool in assisting clinicians with fulfilling these obligations.

Section 3: Mental Health Advance Directives

A mental health advanced directive, or a Psychiatric Advance Directive (PAD), is a legally binding document that details a person’s preferences for future mental health treatment, services, or support (NAMI n.d.). When an individual is “competent to do so,”³ they can consent to temporary treatment and hospitalization in advance of a particular episode (Davis 2008). The guiding force behind this plan is that an individual can make decisions about their healthcare when they may not be considered fully competent to make decisions regarding their treatment. Thus, this empowers an individual to maintain autonomy over time; for even if they refuse treatment at the time it is needed, their refusal can be overridden out of respect for what they had planned for themselves in their contract. At present, 25 states currently have laws permitting patients to create PADs (NAMI n.d.). In the remaining states that do not have specific laws governing PADs, individuals may create a plan under more general statutes connected to health

³ It is beyond the scope of this paper to assert what qualifies as sufficient competency in this case.

care directives (NAMI n.d.). Studies have demonstrated that utilizing advanced directives has been more effective than usual care, chiefly, by assisting in building a trustful relationship between provider and patient, increasing willingness to adhere to treatment plans, minimizing discrimination, and so on (Loubière et al., 2023; NAMI n.d.).

As detailed in the previous section, physicians have an obligation to foster pediatric patients' autonomy by including them in the shared decision-making process. Therapists have a responsibility to discuss the range of possible treatment options and move toward a plan for treatment (Green & Stewart 1987). While adolescents may not be able to create a legally binding advance directive, utilizing this document in care could be an effective means of bolstering their autonomy. Using the standardized form to create a step-by-step plan can open a space for the patient to have their concerns addressed and work towards shared treatment goals. Given the effectiveness of PADs in adult populations and that adolescent patients are on the precipice of legal adulthood, starting this process before reaching the age of 18 could set them up for future successful clinical encounters once they are fully in control of their treatment.

Section 4: Conclusion

Returning to the initial case study, Sam's physician should encourage her participation in developing a treatment plan, thus permitting her to make a Ulysses contract. Her clinician makes sure she understands how harmful going off the medications could be and recommends this is not the best course of action. Initially, Sam is upset but then comes to an understanding that she can reduce her medications or try another combination to reduce the effects of numbness. They draft a plan of action, including intervention if she is at risk of harm to herself or others, and all come to an agreement. Sam feels empowered by her inclusion in the process and validation of her concerns.

While this works for the case of Sam, this is not a broad-stroke recommendation for all pediatric psychiatry patients, as discerning competence and appropriate interventions is an individualized process. Thus, utilizing mental health advance directives should be on a case-by-case basis. However, I asserted that they can be used in appropriate situations as a tool for clinicians to assist in cultivating their patient's autonomy, minimizing discrimination, and maintaining a healthy therapeutic relationship. I acknowledge that this is an idealized account, as further work must be done on assessing and recommending the requisite conditions in which these documents could be utilized and implemented in pediatric care.

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