On the cusp of capacity?
Healthcare decision-making with & for minors

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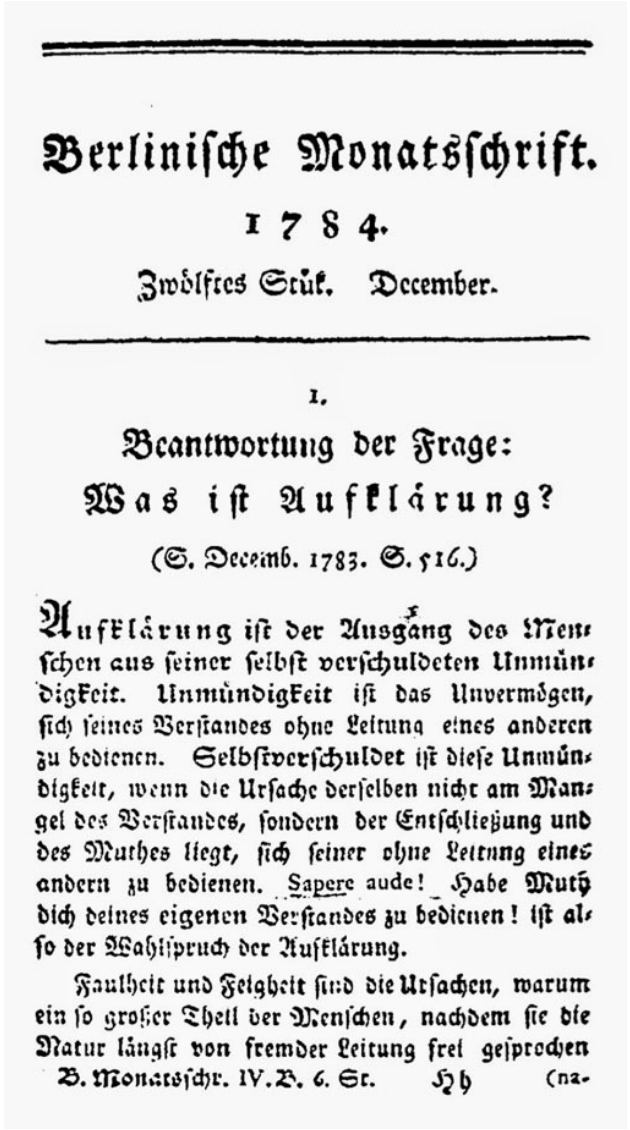

Berlinische Monatsschrift.

1784.

Zwölftes Stük. December.

I.

Beantwortung der Frage:
Was ist Aufklärung?

(S. Decemb. 1783. S. 516.)

Aufklärung ist der Ausgang des Menschen aus seiner selbst verschuldeten Unmündigkeit. Unmündigkeit ist das Unvermögen, sich seines Verstandes ohne Leitung eines anderen zu bedienen. Selbstverschuldet ist diese Unmündigkeit, wenn die Ursache derselben nicht am Mangel des Verstandes, sondern der Entschließung und des Muthes liegt, sich seiner ohne Leitung eines andern zu bedienen. Sapere aude! Habe Muth dich deines eigenen Verstandes zu bedienen! ist also der Wahlspruch der Aufklärung.

Faulheit und Feigheit sind die Ursachen, warum ein so großer Theil der Menschen, nachdem sie die Natur längst von fremder Leitung frei gesprochen

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"An Answer to the Question: What is Enlightenment?"
Immanuel Kant (1784)

Enlightenment is one's emergence from self-incurred immaturity. Immaturity is the inability to use one's own understanding without the guidance of another.

This immaturity is self-incurred if its cause is not lack of understanding, but lack of resolution and courage to use it without the guidance of another.

The motto of enlightenment is therefore: *Sapere aude*!
Have courage to use your own understanding!

Key points

The principles of *respect for persons* and *beneficence* are central to tonight's our conversation.

I will focus on ways the *principle of respect for persons* can and should be actualized in decision making with minors.

To do this, I will present contrasting cases to illustrate the centrality of respect for persons.

TABLE 1 Examples of Pediatric Decision-Making Frameworks and Their Application to the Case

Framework	Description
Best interests standard[55,60]	A tool that considers the highest net interest among the available options. Viewed as an ideal, a standard of reasonableness among multiple competing interests, and as a threshold for intervention in cases of child abuse and neglect.
Harm principle[56]	A tool that identifies the threshold of state intervention to be at the point of serious harm to the child because of parental refusal of treatment. Parental choices need not be in the child's best interests so long as they do not surpass a threshold of harm.
Zone of parental discretion[58]	A tool that aims to operationalize the harm principle when parents and physicians disagree about treatment. Delineates "ethically protected space" wherein parents legitimately make decisions on behalf of children that may not be deemed best but are "good enough" and above the threshold of harm.
Constrained parental autonomy[57]	A tool that allows parents to have the discretionary power to make intrafamilial trade-offs and decisions to account for the interests of other family members as long as the child's basic interests are met. Considers the family as a valuable social institution of child-rearing and self-fulfillment.
IPO framework[61]	A tool that supports shared decision-making between parents and clinicians by placing treatments being considered by the clinical team on the IPO spectrum.

IPO, impermissible-permissible-obligatory.

Table 1. Legally Relevant Criteria for Decision-Making Capacity and Approaches to Assessment of the Patient.

Criterion	Patient's Task	Physician's Assessment Approach	Questions for Clinical Assessment*	Comments
Communicate a choice	Clearly indicate preferred treatment option	Ask patient to indicate a treatment choice	Have you decided whether to follow your doctor's [or my] recommendation for treatment? Can you tell me what that decision is? [If no decision] What is making it hard for you to decide?	Frequent reversals of choice because of psychiatric or neurologic conditions may indicate lack of capacity
Understand the relevant information	Grasp the fundamental meaning of information communicated by physician	Encourage patient to paraphrase disclosed information regarding medical condition and treatment	Please tell me in your own words what your doctor [or I] told you about: The problem with your health now The recommended treatment The possible benefits and risks (or discomforts) of the treatment Any alternative treatments and their risks and benefits The risks and benefits of no treatment	Information to be understood includes nature of patient's condition, nature and purpose of proposed treatment, possible benefits and risks of that treatment, and alternative approaches (including no treatment) and their benefits and risks
Appreciate the situation and its consequences	Acknowledge medical condition and likely consequences of treatment options	Ask patient to describe views of medical condition, proposed treatment, and likely outcomes	What do you believe is wrong with your health now? Do you believe that you need some kind of treatment? What is treatment likely to do for you? What makes you believe it will have that effect? What do you believe will happen if you are not treated? Why do you think your doctor has [or I have] recommended this treatment?	Courts have recognized that patients who do not acknowledge their illnesses (often referred to as "lack of insight") cannot make valid decisions about treatment Delusions or pathologic levels of distortion or denial are the most common causes of impairment
Reason about treatment options	Engage in a rational process of manipulating the relevant information	Ask patient to compare treatment options and consequences and to offer reasons for selection of option	How did you decide to accept or reject the recommended treatment? What makes [chosen option] better than [alternative option]?	This criterion focuses on the process by which a decision is reached, not the outcome of the patient's choice, since patients have the right to make "unreasonable" choices

* Questions are adapted from Grisso and Appelbaum.[31] Patients' responses to these questions need not be verbal.

Appelbaum, Paul S. "Assessment of patients' competence to consent to treatment." *New England Journal of Medicine* 357, no. 18 (2007): 1834-1840.

Capacity/competence in minors

Gillick test

- The child understands the medical issues
- The child understands the moral and family issues
- The child need only have maturity to consent to the specific procedure
- If the child fluctuates between capacity and incapacity, treat as incapacitated.
- Court must be assured child is not simply repeating parents' wishes

Rule of 7's

Capacity in minors

Procedural capacity– many minors over 14 possess ability to consent like adults, but most *do not* use the ability consistently. Why not?

Analytic capacity– possess ability for logical analysis but not use it primarily.

Emotional/real-world capacity– academic studies tell us very little about how decisions are processed in the clinical or research setting where emotions and stressors are high.

All are biologically based limitations of the teenage brain.

Informed consent (in review)

Precondition:

1. Freedom/Voluntariness
2. Capacity for specific decision

Key elements:

1. Provision of information.
   - Standards of disclosure: professional, community, reasonable person
   - Risk/benefit info, alternatives, confidentiality protections, costs/payment, researcher COI
2. Assessment of patient's understanding of information.
3. Voluntary choice is made

Deciding for others (in review)

Pure autonomy

-Because the patient says so.

Substituted judgment

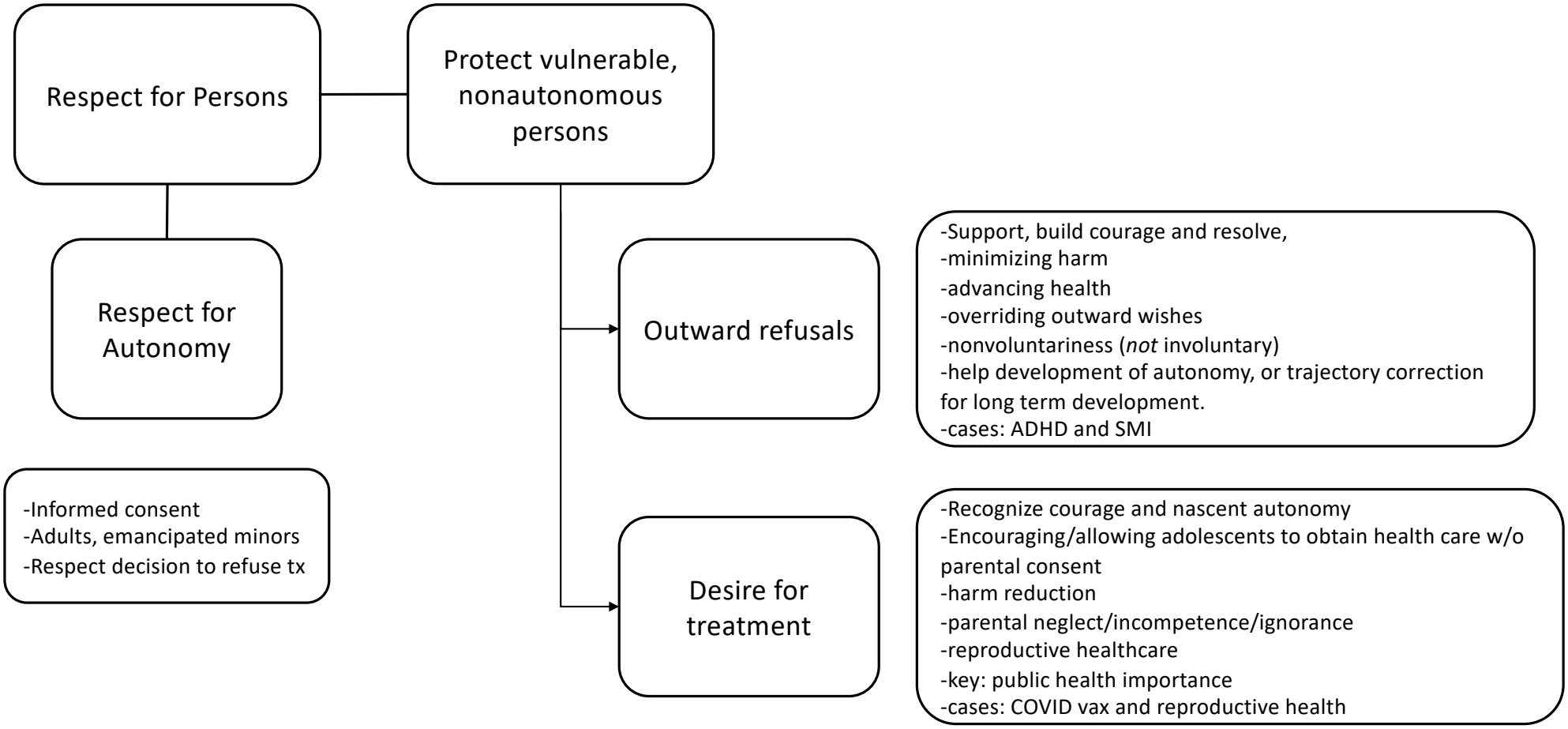
-What would the patient want if she could express her wishes?

Best interests

-We have no knowledge of patient's values; or the patient never had capacity to form values.

Reasonable treatment standard

-No heart transplant for person in PVS even if they 'wanted everything.'


Respect for Persons
Protect vulnerable, nonautonomous persons
Respect for Autonomy
Outward refusals
-Support, build courage and resolve,
-minimizing harm
-advancing health
-overriding outward wishes
-nonvoluntariness (*not* involuntary)
-help development of autonomy, or trajectory correction for long term development.
-cases: ADHD and SMI
-Informed consent
-Adults, emancipated minors
-Respect decision to refuse tx
Desire for treatment
-Recognize courage and nascent autonomy
-Encouraging/allowing adolescents to obtain health care w/o parental consent
-harm reduction
-parental neglect/incompetence/ignorance
-reproductive healthcare
-key: public health importance
-cases: COVID vax and reproductive health

VIEWPOINT

Nonvoluntary Psychiatric Treatment Is Distinct From Involuntary Psychiatric Treatment

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Some of the most ethically challenging cases in mental health care involve providing treatment to individuals who refuse that treatment. Sometimes when persons with mental illness become unsafe to themselves or others, they must be taken, despite their outward and often vigorous refusal, to an emergency department or psychiatric hospital to receive treatment, such as stabilizing psychotropic medication. On occasion, to provide medical care over objection, a patient must be physically restrained.

The modifier "involuntary" is generally used to describe these cases. For example, it is said that a patient has been involuntarily hospitalized or is receiving involuntary medication ostensibly because the patient did not consent and was forced or strongly coerced into treatment. Importantly, a person may be involuntarily hospitalized but retain the right to refuse treatment. "Involuntary" is also used to describe instances when an individual is committed to outpatient treatment by a court. The fact that a person is being treated involuntarily raises numerous challenges; it raises concerns about protecting individual liberty, respect for patient autonomy, and the specter of past abuses of patients in psychiatric institutions.

Although it has become both a clinical colloquialism and legal touchstone, the concept of involuntary treatment is used imprecisely to describe all instances in which a patient has refused the treatment he or she subsequently receives. In some cases, a patient outwardly refuses treatment but may have previously expressed a desire to be treated in crisis or, according to a reasonable evaluator, he or she would have agreed to accept stabilizing treatment, such as antipsychotic medication. A similar scenario occurs in the treatment of individuals who experience a first episode of psychosis and who outwardly refuse treatment. With no prior experience of what it is like to have psychosis, these patients are unable to develop informed preferences about treatment in advance of their first crisis. In these cases, some believe it is reasonable to provide treatment despite the opposition of the patient, although this could be debated.

To more precisely distinguish such cases, clinicians and policy makers should begin to refer to these instances as nonvoluntary, not involuntary, treatment. Nonvoluntary treatment suggests that the patient exists in an intermediate domain of decision-making capacity and voluntariness. In this momentary refusal of care, the patient contradicts long-held values and a deeper desire to be autonomous. This nomenclature may provide additional ethical justification for treating patients who momentarily refuse psychiatric treatment and may provide nuance about challenging cases.

The distinction between the concepts of involuntary and nonvoluntary has been recognized particularly in other areas of biomedical ethics, including critical care, end-of-life decision making, and clinical research.[1] For example, the controversial practice of nonvoluntary euthanasia refers to cases involving a gravely ill patient who lacks capacity or the potential for capacity. Some theories of nonvoluntary treatment stipulate that no knowledge of patient values exists. In the case of psychiatric treatment, nonvoluntary treatment should be considered in a broader sense that allows for evidence of past values, whether explicitly expressed or tacitly demonstrated by a patient's life in the community. Although evidence of previous values would seem to move such cases under the penumbra of voluntary treatment, it seems illogical to refer to any instances of forced psychiatric treatment as voluntary.

Voluntary, Involuntary, and Nonvoluntary Treatment

The distinctions between voluntary, involuntary, and nonvoluntary treatment turn, in part, on patients' capacity to indicate either directly or through a surrogate their wishes and values pertaining to a specific medical decision. Voluntary decisions are typically those made by capacitated patients who are free of coercive influences. These are the decisions that are enacted in clinical or research settings in the final stage of the informed consent process. Involuntary treatments are those imposed on a person who in some way is coerced, incapacitated, or dangerous. For example, involuntary treatment is justified when a patient is found to be an imminent threat to his or her own or another's safety, whether that patient retains decision-making capacity or not.

However, in behavioral health care, the discussion of involuntary treatment usually stops there, missing crucial ethical facets of voluntariness. What are overlooked are the possibilities that a patient may have previously expressed a wish to be treated in crisis, or there exists compelling evidence that the patient was living successfully in recovery and would want to continue to do so. If such facts exist, then interventions that are framed as involuntary are actually something else.

Such treatment should be considered nonvoluntary because, although explicit informed consent may be impossible to obtain and despite a patient's outward refusals of treatment, a clinician may reasonably ascertain that the patient's previously expressed values justify treatment. The concept of nonvoluntary psychiatric treatment recognizes that a patient may have held rational values that were co-opted by a mental illness. This recognition is particularly salient in first-episode

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Teen patients with anorexia nervosa

Forced treatment is controversial

- May make long term treatment impossible
- Highly invasive, may involve tube feeding, constant supervision, etc.
- Likely traumatic to be force to consume.

Level of competence is doubly difficult to determine

- May possess rational skills and appear capacitated, but are not.
- Caloric deficits, malnutrition, cognitive function.
- Emotional and psychological values are ‘pathological’ (Charland).
- Values are unstable and fluctuate (Buchanan & Brock).

Tan DJ, Hope PT, Stewart DA, Fitzpatrick PR. Competence to make treatment decisions in anorexia nervosa: thinking processes and values. Philos Psychiatr Psychol. 2006 Dec;13(4):267-282. doi: 10.1353/ppp.2007.0032. PMID: 18066393; PMCID: PMC2121578.

ETHICS, LAW, AND MEDICINE

Depression and competence to refuse psychiatric treatment

A Rudnick

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Individuals with major depression may benefit from psychiatric treatment, yet they may refuse such treatment, sometimes because of their depression. Hence the question is raised whether such individuals are competent to refuse psychiatric treatment. The standard notion of competence to consent to treatment, which refers to expression of choice, understanding of medical information, appreciation of the personal relevance of this information, and logical reasoning, may be insufficient to address this question. This is so because major depression may not impair these four abilities while it may disrupt coherence of personal preferences by changing them. Such change may be evaluated by comparing the treatment preferences of the individual during the depression to his or her treatment preferences during normal periods. If these preferences are consistent, they should be respected. If they are not consistent, or past treatment preferences that were arrived at competently cannot be established, treatment refusal may have to be overridden or ignored so as to alleviate the depression and then determine the competent treatment decision of the individual. Further study of the relation between depression and competence to refuse or consent to psychiatric treatment is required.

Depression is a common and serious mental disorder. The more severe forms of depression, termed collectively major depression, have a life time prevalence of roughly 10% in the general population.[1] Such depression causes considerable morbidity and mortality to the individuals afflicted, mostly from suicide attempts and physical ill health.[2] It also imposes considerable emotional and financial burdens on families and on society in general.[3] Major depression can be successfully treated by psychiatric interventions, such as antidepressant medications, electroconvulsive therapy, and some psychotherapies.[4] Considering all this, it seems obvious that major depression should be treated. Yet individuals afflicted with major depression may refuse psychiatric treatment, sometimes because of their illness. Hence, we are faced with the problem whether to respect or override refusal of psychiatric treatment by individuals afflicted with major depression.

There is widespread agreement that treatment refusals should normally be respected,[5] that is providing they are arrived at competently[6]; this agreement is based on the widely accepted principle of respect for autonomy.[7] Thus, the problem whether to respect or override (or, rather, ignore) refusal of psychiatric treatment by individuals afflicted with major depression can be formulated—assuming the principle of autonomy is of first priority—as the question whether such refusal is arrived at competently. For if it is, it should be respected (if no other party, such as a depressed mother's child, is seriously harmed by the refusal), and if it is not, it should be overridden/ignored, according to the prevalent autonomy-oriented bioethics. In order to address the problem whether refusal of psychiatric treatment by individuals afflicted with major depression should be respected or overridden/ignored, this paper will illustrate and discuss the question whether such refusal is arrived at competently.

CASE ILLUSTRATION

The patient is a 53 year old north American white woman, divorced, with an adult son and daughter, who has been an inpatient in a tertiary-care mental health centre for the last year because of a prolonged major depressive episode without psychotic features, consisting of diminished pleasure and interest, insomnia, reduced weight, fatigue, lack of energy, poor concentration, and suicidal ideation, all of which considerably impair her ability to live in the community—to the point of starting a fire at home with a cigarette. It is unclear whether this was intentional due to suicidality or neglectful due to poor concentration. She is pessimistic and indifferent regarding the improvement of her condition. She has a history of recurrent major depression, with a couple of suicide attempts since the age of 19, as well as abuse of hypnotic medications. Her previous depressive episodes responded best to electroconvulsive therapy. She has no other notable clinical history and there is no identified recent trigger for her current depression. She has an unremarkable personal and family history, aside from her father having abused alcohol, and she has never worked. During the current hospitalisation, she was given various antidepressant medications that did not improve her condition, after which she and her children consented to her being given electroconvulsive therapy. With electroconvulsive therapy, her depression improved to the extent that she slept better and went back to her old habit of reading books (reflecting improvement in anhedonia and concentration), but her other symptoms persisted. She remained pessimistic and indifferent as to the outcome of treatment, resulting in her wish to be left alone and in her eventual refusal to continue electroconvulsive therapy after eight sessions in spite of attempts to inform her of, and demonstrate to her, the benefits of electroconvulsive therapy, which she knew.[8]

DEPRESSION AND THE STANDARD NOTION OF COMPETENCE TO CONSENT TO TREATMENT

The question of the competence of depressed individuals to refuse psychiatric treatment has not been explored much.[9] This may be due to the fact that the notion of competence to refuse (or consent to) treatment was originally required to address mainly cognitively impaired or psychotic individuals, some of whom are more in the public eye because of an increased risk of danger to others when their mental impairment is not treated, such as in schizophrenia.[10] It may also be

When justified

Evidence of severe suffering.

Risk of further disability, decompensation, progression of illness.

Safety of self or others is at risk.

Beneficial treatment is readily available.

Evidence of values promoting recovery.

Evidence of values

Explicit in a Psychiatric Advance Directive (PAD) or a Wellness Recovery Action Plan (WRAP)

Explicit in words expressed to others.

Implicit in person's words to others.

Implicit in person's life in the community.

Why not just stick with “involuntary?”

Involuntary suggests a person possesses capacity and is refusing an intervention.

Involuntary means the person will be unhappy to receive treatment long-term.

Involuntary suggests treatment is being forced upon the person in opposition to both their 1st and 2nd order values.

Allan Stone's "Thank You" theory

Would the patient appreciate treatment over objection after the fact?

Treatable condition.

Evidence is required.

Evidence suggests younger patients, with schizophrenia and affective disorders expressed gratitude after treatment.

Clinical ethics

PAPER

Assent as an ethical imperative in the treatment of ADHD

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ABSTRACT
The American Academy of Paediatrics endorses obtaining assent when prescribing medications for attention-deficit/hyperactivity disorder (ADHD) in older children whenever possible. Studies indicate the concept of assent may not be well understood by clinicians, possibly effecting effective and widespread implementation. We argue that though the concept of assent continues to evolve, it is critical in the context of patient-centred care, shared decision-making and in supporting minors' transition to adulthood. Based on the principle of respect for young persons, we argue that obtaining assent is an ethical imperative when prescribing medication for ADHD. We highlight the instrumental benefits of obtaining assent in the paediatric clinical encounter when prescribing medications for treatment of ADHD.

INTRODUCTION

The prevalence of attention-deficit hyperactivity disorder (ADHD) among US children has increased two to three times in the last 20 years, and a growing number of preschool aged children are being prescribed stimulant medications.[1 2] With approximately 9% of children in the USA between 9 years and 17 years of age being diagnosed with ADHD and 2.7 million children prescribed stimulant medications annually (Centers for Disease Control, 2010), ADHD is considered the most prevalent and most commonly treated mental health diagnoses in US children.[3 4]

A 2012 survey of parents by the Child Mind Institute and Parents magazine noted that 72% of respondents felt doctors and parents too quickly medicate children for treating ADHD and 63% reported too many children are being diagnosed with ADHD when they 'just have behavioural issues'.[5] This attitude was reflected in one study of parental perceptions of interventions for ADHD comparing behaviour modification, methylphenidate or a combination of the two. Parents consistently rated methylphenidate as the least socially acceptable and behaviour modification as the most acceptable intervention.[6] Despite persistent negative perceptions, the percentage of US children (between 4 years and 17 years of age) taking medications for ADHD increased by 28% between 2007 and 2011.[7]

The increase of stimulant use in children has caused controversy and concern about the potential medicalisation of typical, albeit challenging, childhood behaviours. These concerns are often implicitly related to the perception that stimulants will have a deleterious effect on the child's emerging sense of self and their sense of authenticity.[8] By using stimulant medications, some argue, children may become an ersatz though socially manageable version of themselves.

The publication of the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-5) has provided an update of current clinical diagnostic criteria for ADHD. One key change to the diagnostic category is that age of onset has shifted from 7 years to 12 years. Sceptics of the ADHD diagnosis have expressed concern that this change unjustifiably casts a wider diagnostic net, leading to continued medicalisation and 'disease mongering'.[9] Others who accept the reality of ADHD are concerned that a broader category will create too much demand for access to very limited high quality mental health resources for those with the greatest need.[10 11]

Overarching public concerns about the reliability and validity of ADHD diagnosis and worries about the overprescription of ADHD medications suggest paediatricians should be particularly conscientious in their conversations with parents and children about stimulant use from the beginning. Furthermore, public controversies surrounding the use and potential misuse of stimulants along with concerns of increased prevalence rates suggest treatment conversations should include young patients themselves. Young patients need to understand what they are about to embark upon, what are the risks, benefits and the broader social context within which ADHD medication is to be used.

We therefore first argue that seeking and obtaining a child's assent when prescribing stimulant medications is an ethical imperative based on the bioethical principle of respect for persons: it is intrinsically good to include young persons in their care to the extent that they are competently able to participate in that care. This principle is fundamental to patient and family-centred care, and shared decision-making, and it extends to foundational aspects of clinicians supporting their patient's transition to adulthood. Thus when prescribing psychotropic medications for treatment of ADHD assent is a necessary component of providing high quality healthcare.[12] Second, assent can help avoid negative misperceptions regarding the overprescribing of stimulants and the specific concern that stimulants present a risk to the child's authentic sense of self. We believe that engaging in an ongoing assent conversation with each patient about the physical, psychological and existential effects of their treatment is necessary and feasible with present day clinical time constraints.

Benefits of assent for ADHD treatment:

- Intrinsic: respect for child's emerging autonomy.
- Extrinsic: encourages involvement at crucial juncture from adolescence to adulthood.

Concerns by clinicians

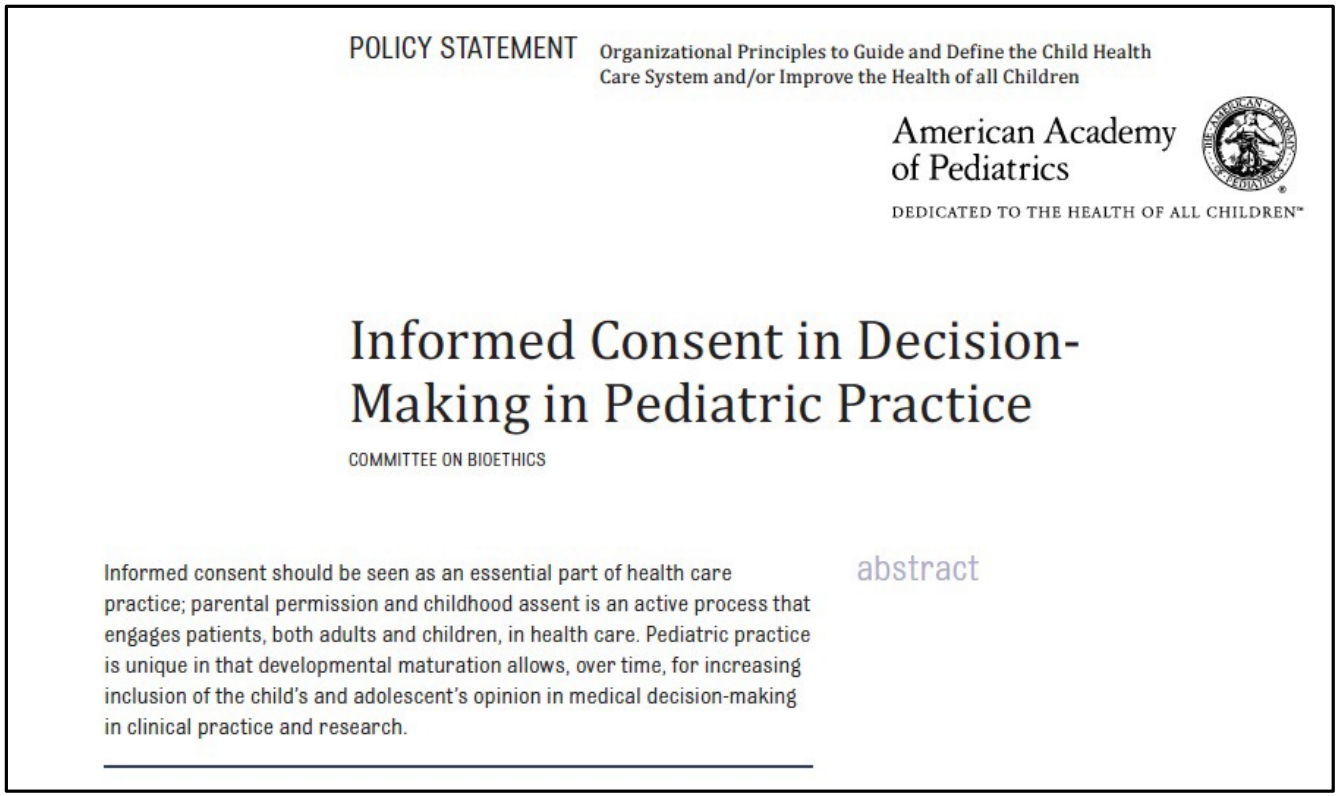
- No Time
- ADHD undermines capacity
- They don't really understand what asset is or entails.

Parental concerns

- Stigma around taking 'stimulants'
- Authenticity will be undermined
- Empirical work by Ilina Singh, et al indicates this is a misplaced concern.
- Asked kids about their feelings with ADHD.

Bottomline:
"Assent actualises, recognises and respects the child's emerging autonomy, and for these reasons clinicians should seek the child's assent in the management of ADHD."

Assent



POLICY STATEMENT Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™

Informed Consent in Decision-Making in Pediatric Practice

COMMITTEE ON BIOETHICS

abstract

Informed consent should be seen as an essential part of health care practice; parental permission and childhood assent is an active process that engages patients, both adults and children, in health care. Pediatric practice is unique in that developmental maturation allows, over time, for increasing inclusion of the child's and adolescent's opinion in medical decision-making in clinical practice and research.

Pediatr 138:e20161485, 2016

Assent elements (AAP, Committee on Bioethics 1995, 2016)

1. Helping the patient achieve developmentally appropriate awareness of the nature of his or her condition.
2. Telling the patient what she can expect with tests and treatments.
3. Making a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy).
4. Soliciting an expression of the patient's willingness to accept the proposed care. Regarding this final point, we note that no one should solicit a patient's views without intending to weigh them seriously. In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived.

Katz, Aviva L., Sally A. Webb, and Committee on Bioethics. "Informed consent in decision-making in pediatric practice." *Pediatrics* (2016): e20161485.

How does assent differ from consent?

Not legally effective by itself

-supplements the proxy's permission

May not require the same level of comprehension or reasoning

Whether or not assent is required depends upon seriousness of consequences and maturity of child.

Weight of child's assent

"Dissent by the pediatric patient should carry considerable weight when the proposed intervention is not essential and/or can be deferred without substantial risk."

"If the likely benefits of treatment in conditions with a good prognosis outweigh the burdens, parents should choose a treatment plan over the objections or dissent of the minor… In general, adolescents should not be allowed to refuse life-saving treatment even when parents agree with the child."

Weight of child's assent

"In medical scenarios with a poor prognosis and burdensome or unproven interventions, more consideration should be given by the physician to advocating for the cognitively mature teenager who wants to refuse treatment and uphold an adolescent's assent or refusal for further attempts at curative treatments."

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Against the Tide: Arguments against Respecting a Minor's Refusal of Efficacious Life-Saving Treatment

LAINIE FRIEDMAN ROSS

In October 1994, Billy Best, a 16-year-old adolescent from Boston, made national television skateboarding in Texas. Billy had been diagnosed with Hodgkin's disease earlier that year. After five sessions of chemotherapy, he had lost 20 pounds and his hair.[1] Billy had observed his aunt die after chemotherapy made her sick, and he too felt the chemotherapy was killing him. He decided to run away after he was told that most of the cancer was gone, but that he would need to continue chemotherapy and receive radiation therapy over the next four months.[2]

A self-described born-again Christian, Billy packed his skateboard and $300 into a small duffle bag, left home, and "put his life in God's hands."[3] His parents, heartbroken and stricken with fear, made an appeal in the national media for him to come home and promised not to force more chemotherapy on him.[4] When Billy returned from Houston to Boston, he and his parents met with the oncologists and explained that they would seek out complementary and alternative medicines (CAM) and use prayer. The physicians reported the family to the Department of Social Services, which tried to have Billy removed from his parents' custody and to have treatment forced upon him.[5] The State of Massachusetts dismissed the case after intense media coverage of the case.[6] Although initially the claim was that Billy would probably die without treatment,[7] the physicians eventually acknowledged that he had received enough chemotherapy that he had a good chance of survival.[8] Billy and his family, on the other hand, claim that he was cured by the CAM and prayer.[9]

Fourteen years later, Billy is, according to his own web site, healthier than ever.[10] He takes two to four ounces of Essiac a day "to keep his immune system boosted" and also does at least two 21-day cycles of 714X per year for the same reason. Billy avoids processed food, red meat, dairy products, and sugar and takes lots of Shaklee supplements. He also continues to enjoy skateboarding. On his web site are links to his book, published by his parents, and to 714X and Essiac herbal formula.[11]

Billy Best is not the only adolescent to make the media for treatment refusal. In 2005, 15-year-old Starchild Abraham Cherrix was diagnosed with Hodgkin's disease.[12] He underwent chemotherapy but was told in 2006 that

I would like to thank Daniel Brudney, Walter Glannon, Ann Dudley Goldblatt, Erin Talati, and an anonymous reviewer for their thoughtful comments on earlier drafts of this manuscript.

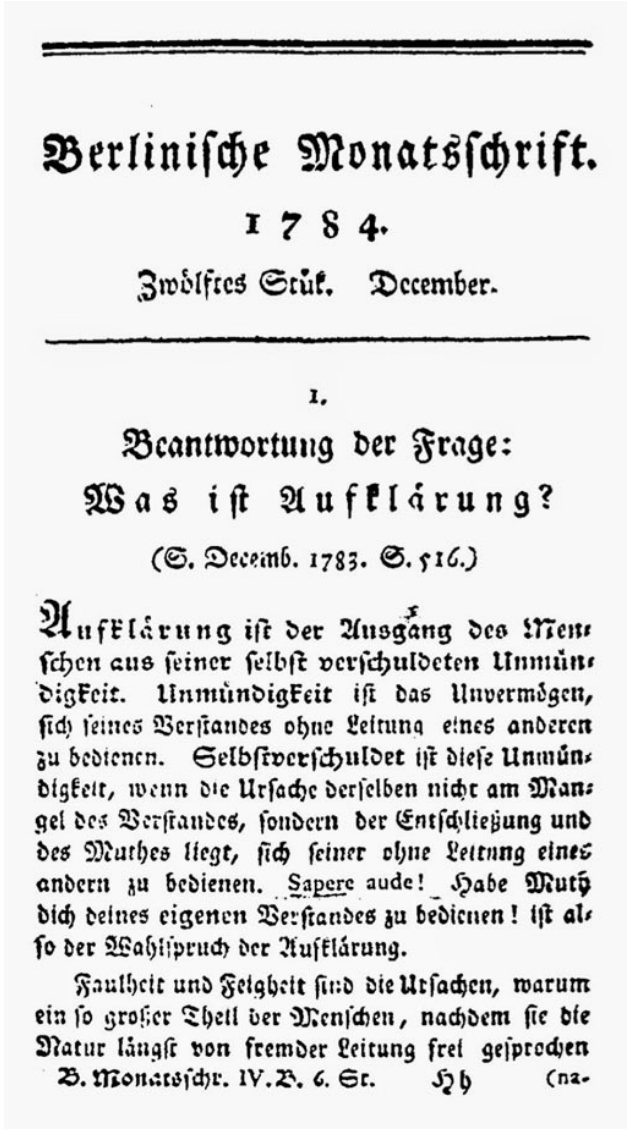
Parents may make life-saving decisions for their child, considering:

1. Obligation to meet minor's basic medical/health needs.
2. Respect for child's present life projects; discounted to a degree.
3. Respect for child's potential for future projects.

Treat mature minor to enhance long-term autonomy.

Recognizing minor has not formed fully as an autonomous being. Time-dependent maturity, cultivation of virtues, etc.

In cases of family refusal, consideration 1 overrides 2 or 3.



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Beantwortung der Frage:
Was ist Aufklärung?

(S. Decemb. 1783. S. 516.)

Aufklärung ist der Ausgang des Menschen aus seiner selbst verschuldeten Unmündigkeit. Unmündigkeit ist das Unvermögen, sich seines Verstandes ohne Leitung eines anderen zu bedienen. Selbstverschuldet ist diese Unmündigkeit, wenn die Ursache derselben nicht am Mangel des Verstandes, sondern der Entschließung und des Muthes liegt, sich seiner ohne Leitung eines andern zu bedienen. Sapere aude! Habe Muth dich deines eigenen Verstandes zu bedienen! ist also der Wahlspruch der Aufklärung.

Faulheit und Feigheit sind die Ursachen, warum ein so großer Theil der Menschen, nachdem sie die Natur längst von fremder Leitung frei gesprochen

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"An Answer to the Question: What is Enlightenment?"
Immanuel Kant (1784)

Enlightenment is one's emergence from self-incurred immaturity. Immaturity is the inability to use one's own understanding without the guidance of another.

This immaturity is self-incurred if its cause is not lack of understanding, but lack of resolution and courage to use it without the guidance of another.

The motto of enlightenment is therefore: *Sapere aude*!
Have courage to use your own understanding!

VIEWPOINT

COVID-19 Vaccination of Minors Without Parental Consent
Respecting Emerging Autonomy and Advancing Public Health

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In May 2021, the Pfizer-BioNTech COVID-19 vaccine received emergency use authorization from the US Food and Drug Administration in adolescents aged 12 to 15 years, with authorization for younger children expected later this year.[1] Despite reported clinical trial data indicating that the vaccine is safe and 100% efficacious for this age range, some parents and guardians may remain hesitant or outright opposed to vaccinating their children, particularly in politically and culturally conservative communities.[2]

Children and adolescents account for approximately 22% of positive COVID-19 cases reported to date, and hospitalizations among this population have recently spiked.[3] Since July 2020, weekly reported case rates for individuals aged 14 to 17 years have generally mirrored or exceeded rates among adults.[4] As cases decline in adults owing to vaccination, the current case rate in teenagers now exceeds that of adults 55 years and older.[5] Although COVID-19 illness is generally less severe in younger people, the disease has nonetheless caused substantial morbidity and more than 325 deaths among US children and adolescents, a burden of disease greater than that of many diseases for which vaccines are routinely recommended in this age group.[6]

Approximately one-third of confirmed COVID-19 cases in minors have been asymptomatic, creating an opportunity for minors to spread the virus unknowingly. The reduction of asymptomatic transmission is essential to slowing the spread of the virus, and growing evidence suggests that vaccination provides substantial public health benefits by decreasing transmission in addition to its direct, individual benefits.[7] For these reasons, there is an urgent need for increased immunization in younger age groups. Vaccinating minors is critical to protecting them from the virus, reducing transmission—especially to higher-risk populations—and continuing progress toward herd immunity.

Children and adolescents have the capacity to understand and reason about low-risk and high-benefit health care interventions. State laws should therefore authorize minors to consent to COVID-19 vaccination without parental permission.

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Minors' Capacity to Consent to Highly Beneficial, Low-Risk Treatments

Before age 14 years, minors are generally thought to lack the cognitive capacity and maturity to make rational health care judgments.[8] Factors such as social pressure, emotional regulation, and planning skills affect minors' ability to make well-considered choices. To account for these developmental facts, laws require parental permission and presume that parents know and will act in the best interest of their children. Despite this presumption, parents and minors might disagree about health care decisions. In the context of vaccination, some older minors may possess a more accurate understanding of the risks and benefits of a vaccine than their hesitant guardians. In younger children, and depending on the intervention, such cases present challenges and may entail judicial intervention.

However, by age 14 years, minors' reasoning begins to track adult decision-making, weighing in favor of respect for minors' autonomy to make health care decisions that advance their health, particularly when these choices have a positive effect on public health. Around this age, adolescents develop cognitive processes—including a metacognitive understanding of decision-making, problem-solving skills, and an ability to commit to choices—that foster competent decisions.[8]

Minor Consent Laws

Most state laws in the US presume that minors lack medical decision-making capacity and therefore require parental consent for most health care decisions, including vaccination. There are exceptions to this requirement for stigmatizing or sensitive interventions, but few states authorize vaccination without parental consent. In 4 states, minors can consent to immunizations for sexually transmitted infections, such as human papillomavirus and hepatitis B, without parental permission.[9] In 5 states, minors are allowed to consent to any medical intervention, including vaccines. Although few states allow minors of any age to consent to such services, several states mirror existing research on capacity to consent, granting minors autonomy at or around age 14 years. Court intervention may also grant a "mature minor"—adolescents who, after clinical evaluation, are deemed to possess competence to consent or refuse treatment—broad authority over their medical decisions.

Some sensitive health services currently accessible to minors may present greater risk and less benefit than the COVID-19 vaccine. Given the risks and the ongoing devastation of the pandemic, as well as the high benefit of vaccination for individual and public health, existing laws authorizing minors to consent to vaccines should be expanded to include COVID-19 vaccination and adopted nationally.

Policy Recommendations

To balance respect for minors' autonomy with developmental realities and parental interests, a policy allowing minors to receive the vaccine without parental consent would use a sliding scale of decision-making authority, granting greater autonomy to minors as they age while also considering the risks and benefits of vaccination. On such a calculus, COVID-19 vaccines offer high benefit and low risk—a profile that lowers the threshold for determining whether a minor has the capacity to make this decision.

The following age groupings offer a guide for minor consent rules for COVID-19 vaccination:

- Healthy children younger than 12 years would not be permitted to consent to vaccination without parental approval. Children older than 9 years with underlying medical conditions for whom the vaccine could offer increased benefits, however, would be exempt from this general prohibition and, after an affirmative evaluation of their competency, may consent.
- Minors aged 12 to 14 years could consent to vaccination without parental approval with support and facilitation from their clinicians and other trusted adult figures. In such cases, clinicians should notify minors' parents of their immunization unless notification might pose a risk to the minor. In such cases, weighing the risk of parental retribution or the loss of the therapeutic relationship against the risk of minors contracting the virus would require a careful case-by-case determination.
- Minors aged 15 to 17 years could provide consent without parental approval. Unlike the younger groups, immunization for individuals in this population should remain confidential.

Even if states grant minors the power to consent to vaccination, states must also continue to promote vaccine acceptance and confidence in all age groups. Routine vaccinations among children and adolescents have declined—particularly during the COVID-19 pandemic—while antivaccine attitudes continue to grow. In an ongoing public health crisis, children and adolescents should not be placed at continued risk due to their parents' hesitancy over COVID-19 vaccines. Although the percentage of parents who may decline to vaccinate their children is currently unknown, the reported hesitancy among adults—including the age groups that include most parents of minors—suggests that this number is likely substantial.[2] Given that children and adolescents account for approximately 22% of the US population, a considerable portion of unvaccinated minors could prolong the pandemic, compromise herd immunity, and expose these minors to preventable risks.[10]

Prior to the COVID-19 pandemic, responses to other vaccination programs demonstrate that it is not merely a theoretical possibility that situations will arise in which well-informed adolescents will want the benefits of COVID-19 immunization despite their parents' wishes.[9] Although limiting provisions for minor consent only to COVID-19 vaccines (and perhaps only during the current public health emergency) may be more expedient and politically feasible, the ethical and public health concerns at stake are not restricted to COVID-19 vaccines. Policy makers and health officials must take action to address these concerns beyond the context of the current pandemic, even if such action occurs at a later time.

Every vaccinated individual counts in the global fight against COVID-19. The ongoing pandemic and its profound consequences for health and societal functioning affirm the urgent need for states to recognize minors' capacity to consent to vaccination to safeguard individual and public health.

ARTICLE INFORMATION

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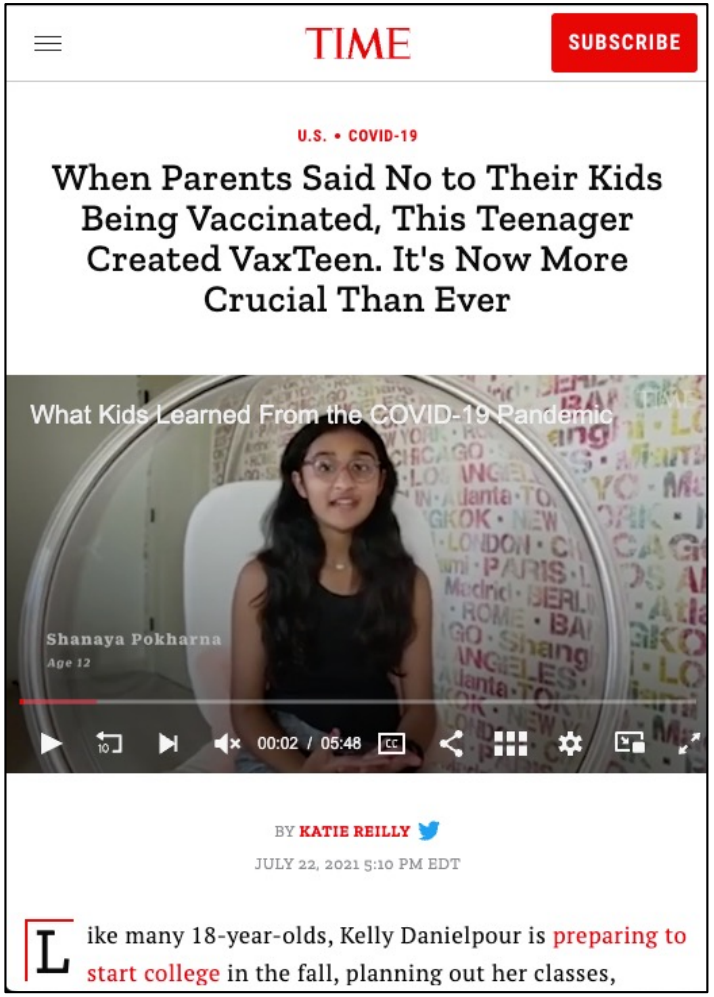
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Shanaya Pokharna
Age 12
00:02 / 05:48
BY KATIE REILLY
JULY 22, 2021 5:10 PM EDT
Like many 18-year-olds, Kelly Danielpour is preparing to start college in the fall, planning out her classes,

Thank you.

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