Making Medical Decisions
CAMS-UA 155
Course Outline

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Course Description:

Do parents always know what’s best for their kids? Should a child be allowed to refuse lifesaving treatment? Is it moral to include minors in research, or maybe morally necessary? When can a teen’s right to change gender outweigh parental permission? In this course, we study the doctor-patient encounter where the patient is a child – a child with family, a child with legal rights, and a child with a developing brain. We review the principles of medical ethics and the concept of informed consent, and focus on the child’s own development in her capacities to reason and make medical decisions in these contexts. We then enter current debates on sexual health, psychiatric treatment, research and end-of-life care, and we raise new question about how doctor’s, kids, and families decide.

In the first section, Theoretical Foundations, we begin with the doctor-patient relationship from Hippocrates and Galen to the present-day and review the distinct responsibility of caring for particularly vulnerable groups, namely children and the psychiatrically ill. The principles of medical ethics - autonomy, beneficence, nonmalfeasance, and justice – are outlined and the clinical encounter is situated within the social contract with perspectives from history, philosophy, sociology, and law.

With Principles in Practice, the second section, we review the doctrine of informed consent as applied to youth and the criteria for capacity to assent, consent, and refuse medical treatment. With findings from neuroscience and developmental psychology, we study how the teenage brain matures, how it makes decisions, and how those decisions are mediated by familial and social influences. Nuances in collaborative decision-making are brought to light regarding confidentiality and research participation, and long held ethical principles are interrogated.

In the final section, Contemporary Dilemmas, we survey controversies evolving in pediatric ethics and mental health, and join current debates on medical innovation. We hone in on healthcare access and delivery, and follow detailed patient narratives for a case-based approach. Experimental trials, so-called cosmetic neurology, and pioneering surgical procedures are introduced. We highlight psychiatric co-morbidities – depression, delirium, post-traumatic stress disorder, attention deficit hyperactivity disorder, and gender dysphoria – that raise fresh questions around capacity and decision-making.
Course Overview:

Section I: Theoretical Foundations

Week 1: Medical Ethics: An Evolving Framework for Youth
We begin with a survey of the physician's oath from antiquity to present day. The distinct responsibility of caring for particularly vulnerable groups, namely children and the psychiatrically ill, are introduced on a background of recognized rights. The primary principles of medical ethics – autonomy, beneficence, nonmalfeasance (do no harm), and justice – are outlined along with the limitations of this traditional framework.

Week 2: Contributions of Moral and Political Philosophy
What is each person able to do and able to be? This is the central question posed by Martha Nussbaum's capabilities approach. In this class, we broaden the context of individual decision-making by situating the clinical encounter within the social contract. We examine the moral position of children in society and consider superimposed systems of justice and fairness. We follow with a study of choice as freedom with thresholds for capabilities, and ask how these positions may be fostered or limited in the health care setting.

Week 3: The Duties of Parents and Children
Here we introduce the constructs of agency and identity as they relate to the child’s role within the family system. We pay special attention to the child’s unfolding development along trajectories of separation and individuation from their family of origin. The concept of relational autonomy is defined and applied to the clinical experience between doctors and patients, children and parents, and doctors and families.

Week 4: The Best Interest Standard, Objections, and State Intervention
Who can act in the child's best interest? In pediatric care, youth are generally presumed to be cared for by parents - parents who are present, parents with parental rights, and parents acting in the best interest of their child. In this class, we are reminded that minors may be emancipated or in alternative custody, parents may withhold or refuse treatment, and families take on all forms of complexity. Lastly, we consider the role of the state for protection, surrogacy, and intervention.

Section II: Principles in Practice

Week 5: Informed Consent, Assent, and Capacity Assessment
In this next section of the course, we review the doctrine of informed consent which requires providing information, assessing the patient’s understanding, and assuring that the patient may freely choose among alternatives without coercion. For older children and adolescents, their assent (affirmative agreement) must often be sought along with parental consent and physician involvement. Unique developmental capacities for participation in decision-making are reviewed, and criteria for capacity in making decisions to consent or refuse treatment are examined.
Week 6: Neurobiology of Adolescent Risk-Taking and Public Policy
How do we determine when a teen should be allowed to drive, earn the right to vote, or be tried as an adult in the court of law? In this class, we examine the neurobiology of adolescent development and how this may inform policy. Studies demonstrate a disconnect between the relatively slow, linear development of impulse control in teens and their hyper-responsiveness to rewards. Mechanisms of impulsivity and inhibitory control are reviewed, and the modulating factors of emotional impact and social influence during adolescence are explored. Finally, we examine the neurobiological underpinnings of adolescent risk-taking behavior, and discuss how such findings should inform public health policy.

Week 7: Neurobiology of Adolescent Decision-Making and the Mature Minor Doctrine
This class will focus in greater depth on the neurobiological basis of adolescent decision-making and its implications for the mature minor doctrine. While guidelines for medical care generally require guardian permission on behalf of minors, findings from neuroscience and developmental psychology indicate that adolescents are capable of making meaningful decisions in exercising their autonomy.

Week 8: Confidentiality and Truth-telling Among Stakeholders
Maintaining confidentiality is both an ethical and legal obligation. Protection of privacy will be detailed along with circumstances requiring disclosure. What they don't know might hurt them. Truth-telling, the act of sharing one’s clinical knowledge and its limitations with accuracy and sensitivity, remains a duty consistent with the principle of veracity. The imperative to discuss health and illness with youth directly is a relatively new phenomenon with its own contextual challenges. Distinct protections for psychiatric, sexual, and substance-use related care contribute additional intricacy.

Week 9: Research with Minors
Is it morally permissible to include minors in research, or perhaps morally necessary? This week we survey the evolution of research ethics and review the Nuremberg Code which established protections for vulnerable populations in the light of WWII's historic abuses. We will revisit debates in pediatric research and explore the difficulties of obtaining informed consent to conduct research with children and adolescents as well as specific ethical imperatives in psychiatric research.

Section III: Contemporary Dilemmas

Week 10: Pediatric Oncology, Experimental Trials and Palliative Care
What rights do youth have to participate in experimental trials and what does this involve? How do parents attend to the voice of their child in surrogate decision-making? And what does it mean to forego life-sustaining care? Recent decades show significant change in the care of children with chronic life-threatening conditions. The treatment approach has shifted from a nearly exclusive focus on management of the disease to an emphasis on the impact of illness on the whole person – physically, socially, and emotionally – and their family system. We examine the case of childhood cancer to closely explore the possibilities of aggressive treatment, palliative care, and so-called futile care in light of a terminal diagnosis.
Week 11: Sexual Health and Reproductive Rights
Kids in different states have different sex education, teens with different parents have variable access to treatment choices, and victims or survivors of sexual assault have widely variable experiences in seeking care. What is reproductive autonomy and what constitutes reproductive coercion? What level of parental involvement is best? In this class, we review the overlapping contours of sexual and psychological health during emerging adolescence and young adulthood. We study how minors access health services for sexually transmitted diseases, contraceptives, and abortions as well as the evidence-based mediators of optimal health outcomes including psychological wellness. We review in detail a case of youth sexual exploitation and track hurdles and opportunities in accessing treatment with an evolving legal landscape. The analysis of trauma’s cumulative sequelae (including impairments in attachment, emotion regulation, and self-concept) precedes examination of related health care disparities, potential re-traumatization in the health care setting, and models of culturally sensitive response.

Week 12: The Vaccine Controversy
Should an unvaccinated student be allowed in your classroom? In your doctor’s waiting room? In this class, we engage in a critical examination of the vaccination controversy and the ethical dilemmas that follow. We review the anti-vaccination movement and the impact of vaccine refusal on children, parents, and doctors as well as society. We consider recommendations for the HPV (Human Papilloma Virus) vaccine to prevent against cancers caused by this sexual transmitted infection. Finally, we explore issues of consent, mandatory vaccination, and public policy.

Week 13: Psychiatric Medications and Cognitive Enhancement
Whose observations are sought to confirm a psychiatric diagnosis? Why are kids from select backgrounds more likely to be diagnosed with attention deficit hyperactivity disorder or more likely to be prescribed medications? And are other kids using the same medications for alternative benefits? Can there ever be distributive justice in psychiatric care? We start our discussion by questioning the validity of psychiatric diagnoses and variability in evidence-based standards of treatment with psychiatric medications. Disparities in access and delivery of psychiatric care are reviewed and the most effective practices for managing children, adolescents, and young adults examined.

Week 14: Gender Identity and Gender Affirmation Surgery
What does it mean to arrest sexual development? When can the teen’s right to self-determination outweigh parental permission? Can irreversible, surgical intervention be justified when the body is ‘healthy’? Should minors have more access to innovative procedures? This class begins with study of two developmental trajectories from early childhood through adolescence: 1) the consolidation of gender identity and spectrum of gender expression and 2) reproductive and sexual development from birth to puberty and beyond. We discuss transgender-friendly primary care, focus on pubertal suppression and surgery for gender transition, and review current guidelines.

A detailed syllabus listing all required readings and assignments will be posted on NYU Classes.