INFORMED DECISION MAKING FOR PEDIATRIC CARE IN THE EMERGENCY DEPARTMENT

BY

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ABBREVIATIONS

AAP: American Academy of Pediatrics
ACEP: American College of Emergency Physicians
AMA: American Medical Association
CDC: Centers for Disease Control and Prevention
ED: Emergency Department
SDOH: Social Determinants of Health
WHO: World Health Organization

ABSTRACT

The informed consent process is a critical component of medical care, promoting the patient's and their family's understanding of the nature of the treatment being provided, as well as any risks or benefits. For most children, their parent or guardian holds the moral and legal responsibility to make healthcare decisions on their behalf. Thus, treating pediatric patients in the emergency department (ED) poses a unique set of ethical challenges given the combined complexities of pediatric care and the environment of the ED. Structural issues such as limited access to primary care, long wait times for appointments, and limited/no health insurance can contribute to parents seeking care for their children in the ED rather than in a primary care setting. Educational issues, including low health literacy and lack of understanding about when to seek emergency care versus primary care, also play a significant role in the increased use of the ED for non-urgent medical needs. This thesis aims to explore the informed consent and treatment decision-making process in the emergency department (ED) as an opportunity to educate parents and improve health literacy.

This thesis begins with a brief overview on the background of informed consent and how the consent process differs in a pediatric setting. Then, a story is presented about a mother and son's ED visit to highlight the structural issues hindering efficient ED care -- highlighting the ethical challenges faced by ED providers who see children with non-urgent conditions. The second chapter explains the current methods of consent used in the ED setting, followed by an ethical analysis of the decision-making process in an ED setting. The third chapter discusses alternative methods of informed consent and treatment

decision-making and the efficacy these methods have for educating parents and guardians about standard-of-care procedures and the proper functions of the emergency room. Lastly, the fourth chapter concludes with recommendations on how educational tools can effectively be deployed in a hospital setting.

INTRODUCTION

In the United States, approximately 30 million children (ages 0-18) are seen in the ED each year (McDermott et al., 2018). Although originally designed to treat urgent medical conditions, the ED has evolved into a refuge for various groups of people with varying levels of medical needs. Accordingly, the number of avoidable and potentially preventable ED visits has increased in the past decade, and these rates are significantly higher for children (Weiss and Jiang , 2018). As a result, emergency room physicians have been given a notable societal role and responsibility to act as health care providers of last resort for many patients who don't have other ready access to care (ACEP, 2017). In addition, as medicine continues to advance, people are becoming more aware of the impact of the social determinants of health. Potentially avoidable emergency department (ED) visit rates are significantly higher for patients with Medicaid or Children's Health Insurance Program/State Children's Health Insurance Program (CHIP/SCHIP) at a rate of (99 visits per 100 people) compared to those with private insurance at a rate of (19 visits per 100 people) (Weiss et Jiang, 2021). There are both structural issues preventing accessible pediatric primary care and educational issues impacting parental health literacies; both aspects create significant barriers to meaningful medical decision-making. The vast majority of pediatric patients seen in the ED are discharged rather than admitted to the hospital (McDermott et al., 2018), suggesting that some of these patients can be cared for outside of the hospital. Alternatively, the ED can provide an opportunity to promote parent/patient education and health literacy.

The multifaceted functionality of the emergency department requires providers and staff to be versatile in their knowledge and skills to be able to treat patients and speak with concerned family members properly. Involving patients or their proxy decision-makers in their care is a crucial component of contemporary medical practice. However, general consent, informed consent, refusal of care, and shared decision-making can be more complex when caring for pediatric patients in emergency settings compared to providing care for adults, mainly due to the unique challenges faced in pediatric practice including, but not limited to, the pediatric patient's age, capacity for decision-making, and guardianship issues (Morrison and Sigman, 2021).

This paper will explore the moral significance of informed decision-making through the informed consent process for pediatric patients and their families in the ED. Alternative methods of informed consent and the efficacy these methods have for educating parents/guardians about standard-of-care procedures and the proper functions of the ED, as well as other health care resources that are available outside of emergency care will be investigated. Incorporating educational interventions into the informed consent process, and throughout the ED visit, may significantly improve health literacy and facilitate informed medical decision making.

My experience as a medical scribe in the ED inspired the idea for this thesis. In spite of being in a non-clinical role, I quickly recognized flaws within our healthcare system and the actionable potential the ED has for improving health literacy and continuity of care for all patients. Despite efforts made by healthcare systems and providers to implement an

effective informed consent process in the ED, physician and patient perspectives on informed consent greatly differ in practice. Working in the pediatric ED, I often found myself answering clarifying questions about standard-of-care procedures, imaging, or follow-up care instructions from pediatric patients and their families.

According to the American Academy of Pediatrics (AAP), "1 in 4 parents have low health literacy, greatly affecting their ability to use health information to make health decisions for their child" (Morrison et al., pp. 263, 2019). Low health literacy significantly impacts medical decision-making for parents. On several occasions parents and their children would return to the ED for the same medical condition, suggesting a lack of follow-up care or non-adherence with follow-up instructions. In reality, a lot of parents most likely did not understand the information that was given to them in the ED, or they simply did not know where else to go.

Unfortunately, due to the limitations of my role as a scribe I was not able to meet all the informational needs of concerned parents and scared children. The moral challenges I faced and the feeling of constantly wanting to do more while working in the pediatric ED led to my interest in clinical ethics. While pursuing my Master's in Bioethics, I became inspired by the patient-centered care model. The ethical and legal requirement of informed consent goes beyond getting permission; it is an opportunity to empower the patient and their family to be an active participant in their health care.

A Story to Consider

Mrs. Smith took her ten-year-old son Max to an emergency room in rural North Carolina around dinnertime, shortly after she had come home from work. He had a frequent cough and sore throat. Mrs. Smith noticed that Max was more tired than usual, but he did not have a fever. These symptoms had begun nearly 3 days before and seemed to be getting worse. Although he was obviously uncomfortable and coughed frequently, Max appeared to be well hydrated and in no acute distress. Mrs. Smith and her family were insured through Medicaid, meaning that Max was insured through North Carolina's Children's Health Insurance Program (CHIP).

Normally, Mrs. Smith took him to a pediatric clinic to receive care but, when she called the clinic yesterday, she was told that there were no available appointments that day. Mrs. Smith attempted to call the clinic again on her way home from work and the person she spoke with recommended that she brings her son to the ED if she was concerned since the clinic was now closed. There are few pediatric clinics in the area, and even fewer physicians in the area who accept new Medicaid and CHIP patients. With growing concern, Mrs. Smith did not feel that Max could wait to see a doctor since the cough had been getting worse and Max has three younger siblings at home.

Upon entering the ED, Mrs. Smith and Max waited hours before being screened. In triage, Max's status was categorized as non-urgent by a third-year Resident working in the ED. Subsequently, they were sent back to the waiting room. As time passed, Mrs. Smith grew angry as staff continued to explain that her son does not require immediate medical

attention and that they would have to wait until an examination room became available, or see their primary care doctor. Mrs. Smith did not know whether to continue to wait or not. She worried about her son's worsening cough and when he would be able to be seen by a doctor. She decided that since they were already there and she was unable to get an appointment at the clinic, she would wait until Max was seen.

Finally, Max was brought back into an examination room. Mrs. Smith quickly went through the registration process. Shortly after, a nurse came in to take Max's vitals. Before she knew it, Dr. J came into the room. Dr. J examined Max and said that they were going to run a few tests to rule out bacterial infections. Mrs. Smith eagerly agreed, and the nurse came back to draw labs. Max's test came back positive for strep throat. Dr. J returned to explain Max's diagnosis and prescribe an antibiotic. Without much explanation or guidance, Mrs. Smith was handed a discharge packet and was instructed to return to the ED if anything worsened with Max. Feeling relieved Mrs. Smith brought Max home.

A few days later Max started to feel much better and was eager to return to school. Mrs. Smith was also ready for Max to go back to school since she had to pay for a babysitter to watch him while she worked all day. That night, Mrs. Smith came back from work and noticed Max was already in his room. Max looked much worse and was complaining of a sore throat. Mrs. Smith immediately called the clinic to try to get Max an appointment. Again, she was told that the clinic was closed and there were no available next-day appointments. Fraught, Mrs. Smith starts to question why Max was sick again since he was already seen by a doctor in the ED and, took the medication he was given. Mrs. Smith was

deeply worried that Max was sicker than when she initially took him to the ED. Left with no more options, she remembered that Dr. J told her to bring Max back to the ED if anything worsened, so she bundled Max up and brought him back to the ED.

Mrs. Smith rushed into the ED and requested to see Dr. J. At the desk, Mrs. Smith was told she would once again have to wait for her son to be seen since he does not require immediate medical assistance. Mrs. Smith waited anxiously with Max in her arms until they were brought back into a room. As soon as the nurse came in, Mrs. Smith expressed her concerns about Max's worsening illness. The nurse noted that Max had a slight fever and went to get him some Tylenol to reduce the fever. Before the nurse came back Dr. J swooped in, re-examined Max and explained that he likely still has strep throat, but he was going to run another set of tests to make sure. Mrs. Smith agreed as the Nurse prepared to draw labs. Sure enough, Max still had strep throat and was slightly dehydrated.

Max was given IV fluids. Mrs. Smith began to cry as the nurse placed Max's IV. Concerned, the nurse asked, "Mrs. Smith are you ok?" and paged Dr. J. Mrs. Smith gathered herself and told Dr. J, "My son is so sick that he needs fluids, is there anything I could have done to prevent this?". At first, Dr. J was struck with this question as Mrs. Smith was clearly a hardworking mother. He then had a realization that Mrs. Smith must not have known that Max is not severely ill and why Max was given IV fluids. After some explanation, Mrs. Smith felt better and questioned Dr. J about the medication he had prescribed since it "didn't work for Max". Dr. J explained that Max must complete the

entire prescription for the infection to be cleared. Mrs. Smith felt relieved as she now understood how long it might take Max to get better.

After discharging Max and Mrs. Smith, Dr. J felt torn about what could have prevented this situation. Part of him felt that if Mrs. Smith had access to better pediatric care for her children or had gone to an urgent care clinic, their return visit could have been prevented. Another part of him felt guilty because he obtained consent from Mrs. Smith for Max's care per the institutional guidelines. He also recognized that Mrs. Smith was unaware that she did not fully understand Max's initial discharge instructions. Dr. J was left questioning how educational interventions can be better implemented in the ED setting to help parents like Mrs. Smith.

CHAPTER 1: SHARED DECISION-MAKING AND INFORMED CONSENT: A BRIEF REVIEW

Section 1: Background of Pediatric Informed Consent - A Brief Overview

Informed consent is an integral part of providing high-quality health care. In the context of pediatric healthcare, informed consent plays a crucial role in promoting the welfare and rights of both children and parents. The doctrine of informed consent was built upon the ethical foundations of human dignity and respect for independent choice (Nelson-Marten and Rich, 1999). Yet, the requirements of what makes consent truly informed are still widely debated. Early discussions about informed consent centered on the idea of preventing disclosure of information that holds the potential to be upsetting or harmful to patients (Beauchamp, 2011). With the emergence of the field of bioethics, emphasis was placed on patients' right to know all pertinent information, including the benefits and potential risks, to come to an informed and autonomous decision. The bioethical principles of autonomy (the right to self-determination and respect for persons), beneficence (protect and promote the best interests of the patient), and nonmaleficence (ensuring safe treatment) are incorporated into the criteria for informed consent (Beauchamp and Childress, 2013).

Over time, the concept of informed consent has undergone significant transformations, shaped by societal attitudes, legal frameworks, and medical advancements. The groundbreaking 1957 case *Salgo v. Leland Stanford Jr. University Board of Trustees* set a legal precedent in the United States by declaring that physicians had a duty to communicate risks and alternatives to patients to enable them to make informed decisions

(Beauchamp, 2011). Although this legal mandate recognized the moral significance of informed consent and informed decision-making for adults with decisional capacity, there were no specifications for pediatric care. It was not until 1985 that the first draft of a pediatric informed consent policy was presented to the original American Academy of Pediatrics (AAP) by William G. Bartholome, MD (AAP Committee on Bioethics, 1995).

There is now a better understanding of how and why physicians should interact with patients and their families when making medical decisions. The AAP states that "patients and their surrogates should be provided with explanations, in understandable, developmentally appropriate language, of the nature of their illness or condition; the nature of the proposed diagnostic steps and/or treatments and the probability of their success; the existence and nature of the risks and anticipated benefits involved; and the existence, potential benefits, and risks of potential alternative treatments, including the option of no treatment" (Katz and Webb, AAP Committee on Bioethics, pp.e4, 2016). This policy, like many others, promotes informed consent as an educational process. However, it is unfeasible to develop a uniform process for obtaining informed consent as the consent process can and ought to vary based on the patient, treatment, and environment.

Section 2: Assent vs. Consent

Oftentimes, children have unmet informational needs in a hospital setting which can cause feelings of anxiety and uncertainty (Bray et al., 2019). To ease these feelings, pediatric providers must cater to the informational needs of the child in an age-appropriate manner whenever possible. By making a pediatric patient aware of the

situation they are in and allowing them to play an active role in their health care, the patient, provider, and parent/guardian can engage in a more collaborative decision-making process. Assent, or approval, from the child is a powerful tool used in pediatric medicine. The American Academy of Pediatrics (AAP) recommends that providers seek the pediatric patient's assent, considering their age, maturity, and capacity to understand the situation, in conjunction with the consent of the parent or guardian (Katz and Webb, AAP Committee on Bioethics, 2016). It is important to note that there are certain situations in which medical treatment must be given, or situations in which the child refuses necessary care. Thus, it must be recognized that obtaining assent from the child is optimal for effective healthcare delivery but may not always be possible, or appropriate, in the ED. The AAP recognizes the moral weight that assent carries in pediatric practice (Katz and Webb, AAP Committee on Bioethics, 2016). Yet, they also recognize the moral challenges faced by pediatric providers when a child's wishes do not align with the ideals of their parent/guardian. Regardless of how that disagreement is resolved, the special focus on assent underscores the desirability of communicating with minors, to the extent possible, as well as with parents.

While assent and consent are intertwined, consent is the legal permission granted by parents or guardians for their child to undergo medical treatment. By obtaining consent, healthcare providers adhere to legal and ethical requirements, considering the parents' or guardians' rights and responsibility to make decisions on behalf of their child. This process is often referred to as, parental "permission" since the parent is deciding on behalf of the child rather than consenting for themselves. However, the term informed

consent is still widely used in pediatric clinical practice so that is the term that will be used for simplicity.

Section 3: General vs. Informed Consent

General consent is required before a patient can be examined and treated. General consent is used broadly in settings where obtaining consent is difficult, like the Emergency Department, or if the risk of undergoing a procedure or treatment is exceedingly minimal (Beauchamp, 2011). In contrast, informed consent is the process in which a healthcare provider educates a patient and/or surrogate about the potential risks, expected benefits, and alternatives to a given treatment or procedure. While both forms of consent are required for ethical and legal reasons, there is a difference between informed consent for specific procedures or treatments and general consent to be treated or examined. It is common for healthcare providers and patients to overlook the importance of thoroughly explaining general consent, especially in a fast-paced environment like the emergency room. Furthermore, for non-emergent medical care or standard procedures, the amount of information that is required to make a truly informed decision depends on the patient's and parents' level of health literacy.

Section 4: Physician vs. Patient Standard

It is evident that there is a difference between the doctrine and the day-to-day application of informed consent (Beauchamp, 2011; Recchia and Braga, 2013). This difference between the legal doctrine, ethical ideal and the practice of informed consent stems from the contrasting needs between the physician and institution, versus the patient and/or family during the consent process. The physician perspective on informed consent tends

to focus mainly on a legally or institutionally required approval (Beauchamp, 2011). On the other hand, the patient-oriented standard of informed consent is centered upon an autonomous authorization or self-determining choice made only when a patient, or their surrogate decision-maker has a substantial understanding of the proposed treatment, alternatives, potential risks, and anticipated benefits of the procedure (Beauchamp, 2011).

The differences between these perspectives are accentuated in the diverse setting of the ED. In the fast-paced environment of the ED, a complete understanding and full disclosure of any given treatment or procedure may be unrealistic. However, individualized care is attainable and necessary in the ED. To alleviate the stress of being in an unfamiliar setting, the physician must make an exerted effort to involve the patient and their family in the decisions being made. The American College of Emergency Physicians (ACEP) advises, "when providing patient and family-centered care when discussing consent, the emergency physician should 1) promote patient dignity, comfort, and autonomy; 2) recognize the patient and family as key decision makers in the patient's medical care; and 3) acknowledge the interdependence of child and parent, as well as the pediatric patient's evolving independence" (American College of Emergency Physicians, pp.368, 2017). Autonomous decision-making and self-determination should serve as the moral framework for improving institutional policies regarding informed consent and information must be tailored accordingly to each patient's individual needs.

Section 5: Consent in the Emergency Department

Given that an unplanned visit to the ED is a vastly different setting from a medical office, the consent process can seem rushed with little information given to parents and children

about standard-of-care procedures such as IV placement, X-rays, and routine lab work. For most people, and more profoundly for those with low health literacy, the ED can be intimidating as there are numerous nurses, providers, and staff coming in and out of the room as well as a variety of patients being treated at any given time in close proximity. For families with limited or no health insurance coverage, the ED is often utilized as a primary care office (Ravi et al., 2021), which emphasizes the lack of accessible healthcare. The multifaceted functionality of the ED requires providers to be versatile in their knowledge and skills to be able to properly treat patients and speak with concerned family members.

For pediatric cases in the ED, informed consent has even more significance due to the added responsibility of obtaining consent from parents or guardians. In most cases, the parent or guardian is present with the minor in the ED or is readily available to provide consent. However, there are occasions when a minor will present to the ED unaccompanied by a parent or guardian. The law recognizes special circumstances in which a minor does not need their parent or guardians' consent to pursue medical treatment or circumstances in which parental/guardian consent cannot be obtained. The "emergency exception rule" or the "doctrine of implied consent" applies when an emergent condition is discovered, and consent cannot be obtained. This rule assumes that if a parent or guardian were present, they would consent to treatment in the best interest of the child (Benjamin et al, 2018). In any emergency setting, hospital staff are advised to make every effort to obtain valid consent without jeopardizing the patient's medical care.

Outside of emergency treatment, there are three situations in which a minor, rather than a parent or guardian, has the legal authority to make decisions regarding their own medical care: legal emancipation, the mature minor exception, and certain medical conditions (Benjamin et al, 2018). Although these laws vary by state, most states consider minors to be emancipated if they are married, monetarily self-sufficient, and not living at home, or if they are on active-duty status in the military (Benjamin et al, 2018). Some states require that the minor must be legally emancipated through the court of law, which can make seeking medical care troublesome for minors who may not have a beneficial relationship with their parent or guardian and are unaware of their rights. The mature minor exception, or the mature minor doctrine, was created for minors who are usually over the age of 14 and demonstrate sufficient maturity and intelligence to understand and appreciate the benefits, risks, and alternatives to the proposed treatment that leads them to a voluntary and reasonable choice (Benjamin et al., 2018). State laws on consent and privacy for minors that pertain to healthcare access are highly variable. Generally, sensitive healthcare services such as substance abuse, reproductive health, sexually transmitted diseases, and mental health, a minor can consent to independently, without the permission of a parent or guardian (Coleman and Rosoff, 2013).

Section 6: Limitations of Informed Consent in Pediatrics

Despite the legal progress made in the past decade to recognize the importance of empowering a minor's emerging autonomy, there are significant limitations to a minor's ability to make their own medical decisions. Primarily, complete confidentiality cannot be guaranteed for minors. Since most minors are covered under their parent's or

guardian's insurance policy, confidentiality can be easily breached. The AMA Code of Medical Ethics Opinion on Consent for minors' states that providers should "inform the patient that despite the physician's respect for confidentiality the minor patient's parents/guardians may learn about the request for treatment or testing through other means (e.g., insurance statements)" (Benjamin et al., pp. 228, 2018). It is imperative that adolescents are made aware that their medical provider cannot ensure total confidentiality. With readily accessible electronic medical records, this issue is even more prevalent. The inability to ensure total confidentiality for a minor creates a morally challenging situation for providers obtaining informed consent for sensitive healthcare needs in the ED. The provider must be able to make an adolescent aware of the potential sharing of information without discouraging the patient from seeking out care in the future. Providing pediatric care in the ED requires providers to be knowledgeable about their state laws and adequately address issues of confidentiality. Since the provider has a fiduciary duty to protect the best interest of the patient, these situations need to be handled with care when it is necessary to involve the parent in the decision-making process.

There are even more limitations of informed consent in the ED. An exploratory study investigating primary caregivers' experience with the informed consent process in the pediatric ED identified the limitations of informed consent in the ED as: "lack of time or proper setting, differing communication styles and expectations between providers and patients, [and] the adequacy of information provided and the understanding and retention of the information" (Wazir et al., pp.408, 2021). Physician time constraints paired with the heightened emotional states of caregivers often leads to a rushed consent process. For

patients and families with low health literacy, it is a challenge to understand what happens in the ED. Areas of improvement identified in this study included "a more thorough discussion of alternatives, a better assessment of knowledge transmission and retention by the PCG [Primary Care Giver] and recognition of the PCG's discomfort during decision making in a stressful environment" (Wazir et al., pp.408, 2021). These findings indicate the need for a more educationally based consent process to be used in the pediatric ED.

The following chapter will delve into the barriers faced by parents, patients and providers that impact informed decision-making in the ED. The first section will provide a brief overview of the Emergency Treatment and Labor Act (EMTALA), which significantly increased the accessibility to emergency care in the United States. Next, section two will discuss the levels of consent used in the ED setting, from implied consent to informed consent. Following, section three will explain the ethical challenges created when the complexities of pediatric care are combined with the busy ED. The final section will explain the substantial impact that parents have on their child's health and healthcare.

CHAPTER 2: CHALLENGES IN OBTAINING INFORMED CONSENT IN PEDIATRIC CARE IN THE ED

Section 1: Emergency Medical Treatment and Labor Act (EMTALA)

Why do people choose to go to the emergency room? The most obvious answer is because they need immediate medical attention; however, in reality many people go to the emergency room simply to access routine medical care. This type of medical care, commonly referred to as non-critical or non-urgent care, is any condition that is not imminently serious or dangerous to life (ACEP, 2023). In contrast, emergent care, or critical care, is any illness or injury that is life-threatening. For concerned parents, bringing their child to the ED seems like the most sensible course of action, not knowing whether symptoms are serious.

The ED is a frequently used care setting because it serves as the frontline of medical services, seeing both critical and non-critical patients. Insurance status and ability to pay for healthcare services has been a long-standing barrier between patients who need care and adequate medical services in the United States. To combat this issue, Congress passed the Emergency Medical Treatment and Labor Act (EMTALA) in 1985 (42 U.S.C. §1395dd). EMTALA is a federal law that guarantees access to emergency medical services regardless of an individual's insurance status, ability to pay, age, national origin, race, or color (ACEP, 2023). It also requires that all individuals presenting to the emergency room receive a medical screening exam (ACEP, 2023). EMTALA also applies to minors. The Center for Medicare and Medicaid Services *State Operations Manual*, specifically states

that “a minor may request emergency evaluation and treatment, and that treatment should not be delayed by waiting for consent from their parent or guardian” (§489.24(a)(1)(i)). Therefore, ED providers have a legal and ethical duty to protect a minor’s life even in the absence of consent. However, if an emergency medical condition does not exist EMTALA no longer applies, and further treatment can wait until consent is obtained (§489.24(a)(1)(i)).

Although this law has prevented hospitals from turning away patients due to a lack of insurance or inability to pay, EMTALA remains controversial. While some view EMTALA as a necessary measure to ensure that the growing population of uninsured and publicly insured Americans can obtain care in a genuine medical emergency, others claim that EMTALA has led to an increase in inappropriate use of emergency medical services in place of primary care (Monico, 2010). For pediatric care, EMTALA raises ethical concerns about the quality of care that is given and what level of consent is required, since not all emergency departments are equipped to effectively treat pediatric patients.

Section 2: Levels of Consent used in the ED

There are three essential components to informed consent: patient capacity, disclosure of information, and voluntariness (Moskop, 1999). In the ED, where there are varying levels of medical conditions and treatments, varying levels of consent are used. The consent process for pediatric patients is even more complex in that as children and adolescents’ mature overtime they can be more involved in medical decision-making (Benjamin et al., 2018). Regardless of the complexities surrounding pediatric consent, disclosing pertinent

information about the care process and any medical treatment is vital to establishing trust and providing high-quality healthcare.

Upon entering the ED, general consent for treatment is typically acquired during the registration process (Silverman, 2016). In a pediatric setting, this general consent is usually completed by the parent or legal guardian and accompanied by providing identification and other demographic information. Given that general consent to treatment is often not obtained by the treating physician, or a nurse, parents may avoid asking questions in an effort to streamline the registration process. In fact, written consent is not required for most standard-of-care procedures, including placing an intravenous line (IV) (Scott, 2018). Although providers are encouraged to inform the parent about the procedure, a concerned and anxious parent may not have a clear understanding of standard-of-care procedures and their indications.

In situations when an emergent medical condition arises, medical providers will not delay necessary medical treatment if a parent is unable to provide consent. This approach is driven by the provider's ethical obligation to seek the best interest of the child (Sirbaugh and Douglas, 2011). Under the law, providers are able to perform stabilizing medical treatment for a minor when consent is not available under what is known as the "emergency exception rule" or the doctrine of implied consent (Sirbaugh and Douglas, 2011). The parents' presumed moral obligation to protect their child outweighs the duty to make decisions on their child's behalf. The AAP Policy Statement *Consent for Emergency Medical Services for Children and Adolescents* states, "reasonable persons would consent

to emergency care if able to do so and that if the legal guardian knew the severity of the emergency, he or she would consent to medical treatment for the child" (Sirbaugh and Douglas, pp.428, 2011). Furthermore, consent can be implied through actions such as a patient holding their arm out for a nurse to take blood. ER physician Michael Silverman writes, "much of what we do in the ER is done with the implied consent of the patient and/or the [general] consent for treatment form patients sign during registration" (Silverman, pp. 4, 2016). It is evident that there is a lack of discussion between patients, parents and providers about routine procedures that do not require written consent.

For more invasive procedures, written informed consent is required. Before a signature is acquired, a discussion about the proposed treatment and its indications ought to occur. The process of parental consent and child assent is at the core of the bioethical principle of respect for persons because it allows parents to make well-informed decisions regarding their child's care (consent and refusal) and allows children to participate in medical decision-making (Tait and Hutchinson, 2018). Therefore, making a well-informed decision requires that the decision-maker understands the information that has been given. The moral significance of informed consent is rooted in an autonomous choice made based on a substantial understanding of the anticipated benefits and potential risks of a given treatment or procedure (Beauchamp, 2011). Thus, obtaining a parent's signature on a consent form is essentially meaningless, from a moral standpoint, if the parent does not have adequate understanding of the information that has been given to them.

Although what constitutes a truly informed decision has been historically debated, the AAP Committee for Bioethics lists several key concepts for obtaining consent and assent in a pediatric setting to best develop patient and parental understanding (Katz and Webb, AAP Committee on Bioethics, 2016). The ACEP *Policy Resource and Education Document* for the Evaluation and Treatment of Minors refers to these key concepts: nature of the illness or condition; proposed diagnostic steps and/or treatments and the probability of their success; the potential risk, benefits, and uncertainties of the proposed treatment; alternative treatments, including the option of no treatment other than comfort measures; assessment of patient and surrogate understanding and medical decision-making capacity, including assurance of time for questions by patient and surrogate; and ensuring that there is voluntary agreement with the plan (Morrison and Sigman, 2021). It follows that truly informed consent in a pediatric setting is dependent upon the provider's ability to educate the patient and parent of these key concepts.

In exceptional circumstances, consent to participate in clinical research can be obtained in the emergency room. However, in an emergent and life-threatening medical situation the unpredictable and time-sensitive environment in the ED, leaves parents unable to thoroughly review consent forms. For this reason, deferred consent was created to be used to recruit patients in emergency research, when informed consent cannot be obtained prior to enrollment (Miller et al., 2022). Although this approach is highly debatable and not used regularly, the idea of deferring consent has obvious application when a child has a life-threatening medical condition and must be treated emergently. Undeniably, this is a situation where providing necessary medical treatment outweighs obtaining consent. For

non-urgent medical conditions, however, this model of consent is unethical and inadequate. Recent research confirms that parents prefer to be provided with an explanation of the research study that addresses their concerns and clearly outlines why the research is being done and how it may benefit future children (Miller et al., 2022). This preference reiterates the notion that the best interest of the child is the utmost priority of parents and providers. Outside of truly emergent situations, consent should never be deferred. Obtaining consent after treatment eliminates the element of choice in the decision-making process.

Section 3: Ethical Challenges Caring for Pediatric Patients in the ED

Caring for pediatric patients in an unpredictable emergency room setting poses distinctive ethical challenges for medical providers. The physician-patient relationship is the moral center of medicine and the defining element in clinical ethics (ACEP, 2017). In pediatrics, this relationship is expanded to include the patient's family in the treatment relationship, making it a tripartite doctor-patient-family relationship.

ED providers see a lot of unplanned, urgent, and occasionally unwilling patients, which can comprise difficult interactions with patients and/or their families. Therefore, emergency medical providers usually cannot rely on established rapport or prior knowledge of the patient's health to effectively communicate with a parent or guardian. Instead, the parent's willingness to seek care and trust the physician is based on broader institutional and professional obligations rather than a long-standing personal relationship (ACEP, 2017). Researchers have studied why parents choose to go the ED over seeking out primary care. Recent studies suggest that child or family sociodemographic characteristics such as

age, race, income, insurance status and social support are associated with avoidable use of the ED (Ravi et al., 2021). This means that emergency room providers are tasked with establishing trust with the child and their parent in a very short amount of time. Effective communication and shared decision-making have been shown to enhance trust between patient's, their families and providers as well as improve treatment outcomes (Katz and Webb, AAP Committee on Bioethics, 2016).

Pediatric readiness in emergency departments has recently gained recognition as a vital aspect in providing optimal healthcare to children. In the United States, over 80% of pediatric emergency room visits occur in general EDs (Gausche-Hill et al., 2015). The influx of non-critical pediatric patients to general EDs raises concerns that these facilities are not equipped to treat the unique anatomic, physiologic, developmental, and medical needs in children that differ from those of adults (Morrison et al., pp.2, 2013). Furthermore, parents need to be educated on when it is appropriate to bring their child to the ED. Addressing ED deficits in pediatric readiness is crucial not only for the critical pediatric patients who require immediate attention but also for the non-critical patients whose well-being and overall health outcomes depend on receiving timely, appropriate, and pediatric-focused care.

The issue of overcrowding in EDs has garnered significant attention in recent years. ED crowding refers to situations where the influx of patients surpasses the facility's capacity to provide timely and efficient care (Gross et al., 2023). One key ethical challenge stems from the allocation of limited resources. In an overcrowded ED, providers often find

themselves in the position of having to decide which patients receive immediate attention. This raises moral questions about how to prioritize patients fairly, considering the urgency of their conditions while also adequately treating pediatric patients who are non-critical (Gross et al., 2023). Providers grapple with balancing the needs of all patients, often under immense pressure due to time constraints.

ED crowding negatively impacts non-critical pediatric patients in several ways. First, increased waiting times lead to delayed care, potentially exacerbating their conditions (Gross et al., 2023). Children, particularly those who are non-critical, require specialized attention and prompt treatment to ensure optimal outcomes. Secondly, the chaotic environment caused by overcrowding may heighten anxiety and distress among parents and young patients, thereby impeding their emotional well-being. Lastly, the quality of care may suffer as providers are forced to multitask, potentially resulting in oversights or errors (Gross et al.,2023).

Addressing the ethical challenges arising from ED crowding requires collective effort from all stakeholders involved. One possible solution to help ease young patients' and anxious parents' concerns is to explain ED wait-times upfront and make them aware of other accessible medical facilities such as urgent care or pediatric clinics.

Section 4: Parents' Impact on Children's Health

Health is affected by many factors beyond access to healthcare. Social determinates of health (SDOH) are the non-medical factors that influence health outcomes. According to

the World Health Organization (WHO), SDOH are "conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life" (WHO, 2018). These determinates include factors such as socioeconomic status, education, neighborhood and physical environment, and access to health care. *Healthy People 2030* organizes SDOH into five domains: economic stability (e.g., poverty and food insecurity) education, healthcare access and quality, neighborhood and built environment (e.g., neighborhood crime and quality of housing), social and community context (e.g., immigration status and social support) (US Department of Health and Human Services, 2020). It is particularly important to consider SDOH among children given that the physical, social, and emotional capabilities that develop tin early life provide the foundation for health and well-being throughout the life course (Sokol et al., 2019). Thus, understanding the complex interplay between socioeconomic status, education, neighborhood, physical environment, employment, and family dynamics is essential in addressing the root causes of preventable ED visits amongst children.

There is an intricate relationship between SDOH and potentially preventable or avoidable ED visits among children. A recent study found that social needs are linked to less preventative care use and greater reliance on emergency care services (Hardy et al., 2021). The greatest social needs for families include limited access to nutritious foods, inadequate housing conditions, and lack of transportation (Hardy et al., 2021). However, there are significant limitations in addressing SDOH that extends beyond the reach of the ED setting. Multilevel structural determinates such as economic instability, limited education and employment opportunities for parents, societal racism, systematic discrimination, and

limited resources, require a multitude of system wide changes (Brown et al., 2019) that are not attainable in the ED. At the minimum, ED providers must be able to recognize SDOH to deliver the best possible care for all children.

One attainable objective to improve non-urgent pediatric care in the ED is promoting a supportive environment for pediatric patients and their families. Effective communication between patients, parents and providers is a vital component in providing high-quality healthcare and supporting informed decision-making. Health literacy is defined as "the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others" (The National Institutes of Health, 2021). Parents' level of health literacy significantly impacts the well-being of their children since they depend entirely on their parents or guardians for medical care access. Furthermore, health literacy affects a parent's ability to make informed decisions regarding their child's healthcare.

Approximately 1 in 3 parents of children presenting to the ED have low health literacy (Morrision et al., 2013). The American Academy of Pediatrics (AAP) specifically states that low health literacy and Limited English Proficiency (LEP) can significantly impact communication and are associated with inappropriate testing, missed diagnosis, increased use of emergency services and poor patient adherence to recommended care (Katz et al., AAP Committee on Bioethcis, 2016). Hence emergency room providers must be able to identify a parent who is having trouble comprehending instructions and offer assistance.

Recommendations for improving parent and child health literacy levels in the ED will be further discussed in Chapter 3.

CHAPTER 3: DIFFERENT METHODS OF INFORMED CONSENT USED IN PEDIATRIC PRACTICE

This chapter will explore different methods of informed consent that have been used in a variety of care settings and evaluate their effect on parental understanding during the pediatric informed consent process. There has been growing recognition of the crucial role that effective communication plays in promoting optimal healthcare outcomes. Specifically, within the realm of pediatric emergency ED visits, clear and concise communication with parents or guardians becomes paramount. Each method presented in this chapter highlights the importance of implementing educational interventions in the pediatric informed consent process.

Section 1: Shared Decision-Making in the Pediatric ED

Recognizing and addressing the ethical complexities surrounding shared decision-making and consent processes in pediatric EDs is fundamental to providing optimal care to young patients. Typically, shared decision-making involves the patient and physician collaborating to build a consensus based on shared information about the preferred treatment that best aligns with the patient's values and preferences (Charles et al., 1997). Unlike competent adult patients who can make decisions for themselves, pediatric patients have some restrictions on their decision-making authority. The main challenge with applying shared decision-making to pediatrics is that it must consider the fact that the patient's surrogate—their parent or legal guardian—is the primary participant in decision-making (Opel, 2018).

Safeguarding the best interests of the child remains a primary ethical concern in the ED. As stated by the American College of Emergency Physicians, "sick and vulnerable emergency patients are in a dependent relationship; they must rely on emergency physicians to protect their interests through competence, informed consent, truthfulness, and the maintenance of confidentiality" (ACEP, pp.5, 2017). Therefore, the power dynamics between healthcare providers and families must be appropriately balanced, ensuring that parents or guardians feel empowered in the decision-making process without being overwhelmed. In addition, providers are encouraged to consider the child's preferences in order to achieve the best possible treatment outcome (Katz et al., AAP Committee on Bioethics, 2016). Also, the capacity of children to understand and contribute to the decision-making process must be carefully evaluated, as it varies with age, cognitive development, and emotional maturity (Katz et al., AAP Committee on Bioethics, 2016).

The formal process of providing relevant information about treatment options and obtaining explicit consent, or assent, can be more important in the ED than in other practice settings because patients and families do not have control over the provider of their treatment, which makes the informed consent process possibly the only readily available way to respect parental autonomy (Moskop, 1999). The remainder of this chapter will explore different methods of informed consent and assess their ability to effectively educate patients and their families on the information required to gain a comprehensive understanding of the medical condition and necessary treatment.

Section 2: Standard Consent

Standardized consent forms are an integral part of medical procedures; however, in an emergency room setting, they may not adequately facilitate comprehension of risks or the voluntary nature of decision-making. Unfortunately, the emphasis on obtaining a parent's signature as documentation of informed consent, or refusal, can diminish the communication process -- especially given the time-pressurized aspect of emergency rooms (The Joint Commission, 2016). Parents or guardians, already under immense stress, may find it difficult to grasp complex information or consequences in a short span of time.

Which treatments and procedures warrant a standardized consent form vary from state to state. As previously discussed, procedures deemed low-risk routine standard-of-care do not require documentation of informed consent. There is even more variability in the use of written consent forms for non-emergent procedures among pediatric emergency departments (Edwards et al., 2019). For procedures that carry a higher level of risk for complications, increased levels of pain, or require radiation exposure, standard consent forms are both ethically indicated and legally required (ACEP, 2017). Common scenarios that require written informed consent for pediatric patients in the emergency room are most surgeries, blood transfusions, some blood tests (like HIV testing), radiation (CT scans, X-ray, etc.), and any use of anesthesia. A 2019 study investigating variability in the use of written consent in pediatric EDs found that "written informed consent was most commonly obtained for procedural sedation (82.5%), blood transfusion (72.9%), and lumbar puncture (66.5%). Twenty-one institutions (32.8%) had policies specifying procedures requiring written consent. Thirty-five institutions (54.7%) used "blanket" consent-to-treat forms"

(Edwards et al., pp. 1509, 2015). These results make it evidently clear that a standardized approach to consent is not plausible for obtaining adequate informed consent. Instead, providers ought to aim for an individualized approach to consent that focuses on delivering pertinent information in a manner that best suits the patient or surrogate decision-maker.

The legal doctrine of informed consent requires that physicians provide the patient (or surrogate decision-maker) with relevant information needed for them to exercise their decision-making rights (AMA Code of Medical Ethics, 2016). This requirement is ambiguous, in that what information is considered relevant will change based on the person who is the decision-maker. In attempting to standardize what information constitutes relevancy in medical situations, the reasonable person standard was created. The reasonable person standard "requires the physician to disclose information that a reasonable person in the patient's condition would need and want to know" (AMA Code of Medical Ethics, pp. e3, 2016). However, there are a multitude of factors that influence the level of information one would need to come to an informed decision. These factors can include education, socioeconomic status, emotional state, and the treatment in question, none of which are consistent from person to person.

The Centers for Medicare and Medicaid Services (CMS) outlines the minimum elements of a properly executed consent form. These elements include: the name of the hospital where the procedure or other type of medical treatment is to take place; the name of the specific procedure, or other types of medical treatment for which consent is being given; the name of the responsible practitioner who is performing the procedure or administering

the medical treatment; a statement that the procedure or treatment, including the anticipated benefits, material risks, and alternative therapies, was explained to the patient or the patient's legal representative; signature of the patient or the patient's legal representative; and the date and time the informed consent form is signed by the patient or the patient's legal representative"(§482.24(c)(2)(v)). The regulation also explains that "Material risks could include risks with a high degree of likelihood but a low degree of severity, as well as those with a very low degree of likelihood but a high degree of severity. Hospitals are free to delegate to the responsible practitioner, who uses the available clinical evidence as informed by the practitioner's professional judgment, the determination of which material risks, benefits, and alternatives will be discussed with the patient"(§482.24(c)(2)(v)). Thus, these forms can be extremely lengthy and often contain medical terminology that makes a genuine understanding of the medical process difficult for those who are not familiar with a healthcare setting. The sole purpose of the pediatric consent process is to foster understanding and encourage shared decision-making between the parent, patient, and provider. These forms must be supplemented with adequate discussion between the provider and the parent, and if appropriate the patient as well.

Section 3: Event-Based vs Process-Based Consent Model in the Pediatric ED

The pediatric consent process in the emergency room is vastly different from other medical settings given that when consent is obtained will vary based on the medical urgency and necessary treatment required in each situation. For this reason, the emergency room typically utilizes two primary models: event-based and process-based consent. The event-based consent model focuses on obtaining consent for each individual procedure or

intervention (Lidz et al., 1988). In this model, consent is obtained from parents or legal guardians immediately before a specific medical intervention is performed. This approach prioritizes a direct and immediate consent process, ensuring that parents or guardians are informed of the intended procedure and agree to it on a case-by-case basis (Lidz et al., 1988). Since the ER is unfamiliar to most parents, an event-based consent model is not ideal for non-urgent care because it hinders the parents' understanding of the evolving treatment plan.

In contrast, the process-based model seeks to incorporate the patient (or surrogate decision-maker) into the ongoing conversation that is a regular component of the diagnostic and treatment process (Lidz et al., 1988). Process-based consent is a more collaborative approach as it encourages the parent and patient to become more involved in the care plan. Since the ER is fast-paced, a process-based consent model is better adapted to informing the parent at all stages of the treatment process (Usher and Arthur, 1998). It is easier and clearer to convey the reasoning and necessary steps of the care plan if there is an ongoing conversation.

Since ED providers do not have a pre-existing relationship with a parent in an emergency setting and unplanned clinical interventions may be necessary, providers must be prepared to routinely assess parent (and patient when deemed capable) understanding of information (Tait and Hutchinson, 2018). This information includes, but is not limited to, standard-of-care procedures, diagnostic testing (X-Ray, CT scans, etc.), and medications. Children also benefit from being included in their own medical care. A recent study investigating the

information needs of children having clinical procedures in the hospital found that "children value a scaffolded approach to gaining and building up information and understanding about a planned procedure" (Bray et al., pp.738, 2019). It is reasonable to suggest that using a process-based consent model in the ED would have the same effect.

Section 4: Electronic Based Informed Consent

Through the utilization of technological advancements, electronic-based consent has become a nuanced method to enhance the consent process. The use of technology in the consent process has many advantages, by incorporating images, animation, and video content that aid comprehension by patients with lower health literacy. This makes it possible to deliver information both synchronously and asynchronously and to tailor the content to individual patients (Pétré et al., 2019). This refers to the multimedia principle. This multimedia strategy is an evidence-based approach developed on the principle that people learn at a deeper level through pictures and words rather than through words alone (Mayer, 2009). Multimedia includes pictures and videos.

The use of a multimedia intervention (MMI) during the informed consent process was found to significantly reduce parental anxiety before and after surgical intervention (Paton et al., 2018). Multimedia interventions have also shown promise in facilitating the informed consent process in the pediatric ED. A parallel group randomized control trial comparing conventional discussion with a video intervention found that parents in the video group had greater levels of knowledge about pediatric procedural sedation in the ED and satisfaction with the informed consent procedure (Lin et al., 2022). However, some parents may have

concerns regarding the security of personal health information or may be unfamiliar with using technology in a healthcare setting, requiring additional support and education.

Section 5: The Teach-Back Method

One of the most pressing challenges in obtaining consent in a pediatric setting is accurately assessing parental understanding. One method to do so is known as the "teach-back" method, which asks the recipient of the intervention to explain what information they have received. This method can be used for audiovisual interventions, digital interventions, and verbal discussions (Glaser et al., 2020). The teach-back method offers a structured system to assess parental understanding, ensuring, to the extent possible, that medical information is effectively conveyed. This technique promotes active rather than passive communication, allowing healthcare professionals to identify and address any misconceptions or gaps in comprehension (Seely et al., 2022). Providers must be cautious not to interrogate or overly pressure the parent. By inviting parents to explain information using their own words, healthcare providers can tailor their explanations to meet the needs of each parent, thus improving overall understanding.

A systematic review conducted in 2022 found that "100% (8/8) of interactive interventions with test/feedback or teach-back components resulted in improved patient comprehension compared with standard informed consent" (Glaser et al., pp.137, 2020). The teach-back method can also help ease the stress that can be felt during the informed consent process. A 2018 study found that ensuring patient understanding reduces anxiety and stress levels, leading to improved cooperation and adherence to treatment plans (Paton et al., 2018). In

the ED, teach-back methods have also been effective in confirming learning and helping patients remember key information (Samuels-Kalow et al., 2016).

While the teach-back method offers numerous benefits, its successful implementation in the pediatric ED faces some challenges. Time constraints, language barriers, and cultural factors may hinder the effective use of the teach-back communication strategy (Katz et al., AAP Committee on Bioethics, 2016). Pediatric providers in the ED must be diligently mindful of perceived bias, especially when communicating with parents who have limited English proficiency and/or low health literacy. An interview study revealed that participants with limited health literacy were concerned about perceived provider judgment during the consent process (Samuels-Kalow et al., 2016). However, by utilizing a patient-centered approach and providing appropriate resources, these challenges can be mitigated, paving the way for successful implementation. With appropriate resources and a patient-focused approach, the teach-back method can become an invaluable tool in facilitating parental comprehension, ultimately improving the quality of care provided to children in pediatric EDs.

CHAPTER 4: CRAFTING OPTIMAL APPROACHES TO PEDIATRIC CARE IN THE ED

The emergency department, often bustling with activity, is unrivaled in terms of accessibility and availability. These aspects make the ED an opportune place (sometimes the only place) to provide patient education to a large number of patients, specifically to those with low socioeconomic status and low health literacy (Pétré et al., 2019). ED providers serve a diverse range of individuals, including critical patients, non-critical patients, children and concerned parents, who can all greatly benefit from the educational opportunities presented within this dynamic healthcare setting. Thus, the ED has the potential to address the issue of low health literacy among a "captive audience" of parents and offer valuable educational resources to enhance their understanding of their child's health. This chapter will provide recommendations on how the informed consent process can be transformed into an effective educational process for conscientious parents and guardians. In addition to reforming the informed consent process, this chapter will show how the ED can be used instrumentally as a setting to provide resources that improve health literacy and informed decision-making.

These recommendations are centered on the assumption that the parent and child have a positive relationship and, except for extreme circumstances, the child returns home to be cared for by their parent, guardian, and/or family. It should be recognized that unfortunately this is not the situation for many children that present to the ED in need of help and protection. Healthcare providers have an ultimate responsibly to protect the

welfare of the child, which in some cases may require the involvement of law enforcement or other parties if the child is being harmed.

Section 1: Patient-and-family-centered Care in the ED

For educational interventions to be effective in the sensitive environment of the ED, they must be incorporated into the shared-decision-making process in a manner that respects the role of both the parent and child in the child's healthcare, while not inflicting bias, being condescending or patronizing. To advance beyond the archaic paternalistic approach to medical practice, the American Academy of Pediatrics (AAP) supports the use of patient-and-family-centered care in the ED (Dudley et al., 2015). Patient-and-family-centered care is an approach to healthcare that ensures the health and well-being of children and their families by recognizing the integral role of the parent, thereby, encouraging a mutually beneficial collaboration between the patients, family, and health care professionals (Dudley et al., 2015). Enforcing this approach for all non-critical pediatric cases can open the door to addressing issues of low health literacy among parents and offering them valuable educational resources to enhance their understanding of their child's health, while in turn, strengthening the process of obtaining "true" informed consent.

Patient-and-family-centered care embodies the idea that care is provided for the patient as a person, not just a condition, and that person is best understood in the context of their family, values, and culture; this model posits that respecting this context will lead to better healthcare, safety, and patient satisfaction (Dudley et al., pp.256, 2015). Without doubt, the emergency room setting presents obstacles that make patient-and-family-centered-care challenging to implement. Some of these challenges include overcrowding (Gross et al.,

2023), lack of pediatric readiness (Remick et al., 2018), the use of hard-to-understand consent forms (Engel et al., 2009) lacking basic information (The Joint Commission, 2016), parents' unfamiliarity with the ED (Dudley et al., 2015), and understaffing (Dudley et al., 2015).

A possible solution to some of these challenges is having other members of the care team, not just the physician, inform parents routinely throughout their child's time in the ED. All aspects of an ED visit, including time spent in the waiting room, present an opportunity to provide educational resources to patients and their families. The benefits of interprofessional collaboration in providing patient education in the ED is well supported (Pétré et al., 2019; Dudley et al., 2014;). The AAP technical report titled *Patient- and Family-Centered Care of Children in the Emergency Department* states, "embracing the philosophy of patient-and-family-centered-care across disciplines (such as nursing, interpreter services, child life and social services, chaplaincy, or mental health services) can promote patient safety, comfort, and satisfaction" (Dudley et al., e257, 2015). This may require extra training and support staff such as translators. Despite these challenges, the patient-and-family-centered care approach offers a promising framework for improving the educational component of the pediatric consent process for stand-of-care procedures in the ED.

Section 2: Optimal Timing

One of the key components to leveraging the ED for patient education is selecting the optimal time to educate concerned parents so that they not only understand the specific information that is given to them about a condition, treatment, or procedure, but also basic

information such as why they are waiting, in a manner that helps them retain that information. The ED presents many opportunities to provide patient education to parents. During the traditional informed consent process in the ED, a large amount of information is given at once, which may lead to patients and their family members struggling to understand how the treatment or procedure will progress as well as how to make treatment decisions (Lin et al., 2022). A research study examining comprehension of ED treatment course and instructions found that majority of patients and caregivers have comprehension deficits across all domains of the ED visit, including diagnosis and cause, ED care, post-ED care, and return instructions (Engel et al., 2006). This evidence suggest that parents and children would greatly benefit from being informed throughout their ED visit and not just when a signature is needed. A practical approach to improving the consent process may be to provide pertinent information and asses parental understanding across the entire ED visit, rather than just during documentation of consent.

An additional area where parental understanding of the ED course can be assessed, and educational interventions can be used, is during the discharge process. Ensuring that parents have an accurate understanding of their child's diagnosis, treatment given in the ED, and follow-up instructions is imperative to improving patient outcomes and continuity of care, in turn, decreasing inappropriate use of emergency medical services (Ravi et al., 2021). Multiple recent studies suggest that using educational tools during the consent process and the discharge process is optimal for improving parental understating and patient treatment outcomes (Pétré et al., 2019; Paton et al., 2018; Bray et al., 2019).

Therefore, to improve parental education in the ED, providers and hospital staff must make a collaborative effort to inform patients and parents throughout the ED course.

Section 3: Method of Consent

In order to avoid parents perceiving the decision as an action confined to a restricted and brief period, information must be given throughout the ED visit. This requires a method of consent that can adapt to the various levels of needs in the ever changing environment of the ED --reflecting a patient-and-family-centered care model. As previously stated in Chapter 3, the process-based consent model may prove to be successful in an ED setting. A process-based consent model is better suited for addressing uncertainties in decision-making than the traditional event-based model because there is a continuing dialogue between the patient and provider (Recchia et al., 2013). Involving parents in the treatment process, regardless of how brief the visit, can empower them to play an active role in their child's healthcare. A study investigating interventions to improve parental understanding of consent for medical and surgical procedures, found that parents who felt more involved in their child's care showed greater understanding of discharge instructions, and were more likely to follow-up at the outpatient clinic (Glaser et al., 2020). Through continuous communication and collaboration between the parent and provider, meaningful decision-making and long-lasting knowledge can be provided in the fast-paced setting of the ED.

Another method of informed consent that may show promise in the ED setting is the teach-back method. The teach-back method has been shown to improve shared-decision-making, comprehension, and physician trust (Seely et al., 2022). There is limited information on

the use of teach-back methods in the ED; however, recent studies have shown promise. An in-depth interview study conducted in 2016 found that adult patients and parents felt that teach-back methods were helpful for confirming understanding and recalling key information (Samuels-Kalow et al., 2016). These results confirm earlier findings that the teach-back method had a positive impact on recall of ED discharge instructions regardless of age or education level (Slater et al., 2013).

These findings indicate that teach-back methods could improve the informed consent process in the ED. Specifically for parents with low-health literacy, the teach-back method presents a possible framework for a more patient-and-family centric consent process. The American Academy of Pediatrics encourages the use of teach-back methods to improve the health-literacy of parents (Katz et al., AAP Committee on Bioethics, 2016). If properly implemented in the ED, the teach-back method could help bridge the knowledge gap between providers and parents through consistent comprehension checkpoints. Healthcare professionals must be perceptive to the parents' needs and create a "shame-free environment" by avoiding asking condescending questions. Use of interpreters may be required when a language barrier is present.

Section 4: Incorporating Educational Interventions

Educational interventions play a significant role in aiding understanding of medical procedures or treatments, especially for those who struggle with health literacy. Simplifying complex medical jargon by providing easy-to-understand explanations can help parents comprehend and retain essential health information. Beyond just simplifying

words, incorporating other media into the consent process can lead to more meaningful learning (Mayer, 2009) and in turn, more meaningful consent.

Various forms of media can be effective in this setting, whether they are pictures, diagrams, or videos. Using visual aids during the consent process has shown promise in the pediatric setting (Rosenfield et al., 2018; Paton et al., 2018; Glaser et al 2020). For example, when using a visual aid in conjunction with the standard consent process for families of children with appendicitis, visual aids improved knowledge, comprehension, and retention of information (Rosenfeld et al., 2018). Likewise, the use of a video intervention compared with conventional discussion to inform parents about pediatric procedural sedation in the ED significantly improved parents' knowledge about the procedure and satisfaction with the consent process (Lin et al., 2022).

Visual aids can also lessen anxiety associated with the unfamiliar environment of the ED. A study conducted in 2020 investigating the use of multimedia (MMI) teaching, in the form of a power-point presentation, during the informed consent process found that MMI significantly reduced parental anxiety during the consent process for infants undergoing surgery (Paton et al., 2020). These methods can also be used to accurately describe standard-of-care procedures to children. In children ages 5-11 undergoing a routine MRI scan, the use of an animation during the consent process improved knowledge, reduced anxiety, retained attention and was enjoyed by the participants. This body of research offers a compelling reasoning for incorporating educational multi-media modes of consent in the pediatric emergency department.

These forms of multi-media can also greatly diminish language barriers that exist in the ED. The American Academy of Pediatrics (AAP) encourages the use of visual aids to address issues of low health literacy and limited English proficiency in the pediatric setting (Katz et al., AAP Committee on Bioethics, 2016). A scoping review of the use of visual aids in health education materials concluded "visual aids developed with persons with low literacy demonstrated statistically significant improvements in health literacy outcomes, with benefits in medication adherence and comprehension also reported" (Mbanda et al., 2021). Recognizing cultural diversity is crucial when designing educational interventions. Tailoring materials and approaches to specific cultural contexts can ensure maximum comprehension and engagement (Glaser et al., 2020).

CONCLUSION

The story of Mrs. Smith's experience with her son Max in the ED illuminates the ethical challenges that can arise in the context of avoidable and primary-care-preventable pediatric ED visits. Before Max's first visit, Mrs. Smith was unable to get an appointment for Max at the pediatric clinic; this left her feeling like she had no other option than to bring Max to the ED. Anyone could have been in Mrs. Smith's situation with inaccessible care; however, social determinants of health also had an impact on Mrs. Smith's decision-making abilities. Strep throat is an example of a primary-care-preventable ED visit, because the infection must be treated but does not require emergency medical intervention. With a new focus on parent and patient education in the ED, Mrs. Smith and Max's first ED visit could have gone much differently, which most likely would have prevented their second visit. There are various opportunities during their time in the ED that could have been used to educate Mrs. Smith on treatment course, standard-of-care procedures, proper medication dosages and resources that can be utilized outside of the ED.

First, during their initial visit to the ED Mrs. Smith and Max were confronted with long wait times before Max received a medical screening exam. During this wait time, a triage staff member could have talked to Mrs. Smith about the expected wait time and even asked questions about Max's symptoms. Even before consent is obtained, parents can be informed about the treatment process in the ED and perhaps redirected to an urgent care or other medical facility when appropriate. The idea of redirecting non-urgent complaints in the ED to outside primary-care facilities has become a quality improvement initiative in EDs across the United States (Wolsski et al., 2022). The SMART AIM project showed that

non-urgent patients can be efficiently redirected to their primary care office for a same day visit from a pediatric ED setting (Wolsski et al., 2022). This system shows the potential the ED triage process has for aiding parent education and a patient-and-family-centric care model. Similarly, during the medical screening exam the Resident could have talked to Max about his symptoms and inform Mrs. Smith about the purpose of the medical screening exam. This can also be an opportunity to reassure Mrs. Smith that Max is going to get the care he needs. In turn, effective communication in the waiting room and during triage could have prevented Mrs. Smith from feeling angry and ignored by staff. Evidently, Mrs. Smith may have also been redirected to a pediatric urgent care or pediatrician office.

Once brought back into the examination room, the registration process can serve as another educational opportunity. Although a non-clinical role, the register can walk Mrs. Smith through the registration process and prepare her for the next person who will enter the room. Creating a continuous flow of communication with parents throughout the ED visit can ease their anxiety in a stressful environment. In the ED, nurses play an essential role in delivering bed-side care and tending to the emotional needs of patients and concerned family members. Therefore, the nurse also has the responsibility to inform Mrs. Smith and Max. While taking Max's vitals, the nurse can explain what vitals are being checked, how they are being checked, and why they need to be checked. Hearing this information can help parents understand basic medical care.

Often rushed, the provider may have limited time to diagnose and treat the patient. Dr. J, the ED attending, briefly explained that Max was being tested for strep throat. In a timely

manner, Dr. J could have assessed Mrs. Smith's understanding of the testing for and diagnosis of strep throat. Using the teach-back method, Dr. J can easily assess Mrs. Smith's understanding of Max's diagnosis and antibiotic instructions. Since Mrs. Smith was unaware that she was not fully understanding the information given to her by Dr. J, she did not ask any questions for Dr. J to see how she had interpreted the information. In addition, Dr. J could explain strep throat and the importance of taking the entire antibiotic prescription, using simple language that aligns with Max's cognitive level. Further, Mrs. Smith could have been given a simple handout or brochure that has an illustration and instructions on the proper dosage of antibiotics that she could have referred to outside of the ED. At a minimum, Mrs. Smith should have been explicitly told that Max had to complete the antibiotic entirely even if his symptoms subside – a message the pharmacist could also reinforce.

During discharge, Mrs. Smith was given a lengthy discharge packet that was not easy to understand which may have contributed to her bringing Max back to the ED. Creating discharge information that is in easy-to-understand language, with helpful definitions and informative pictures or diagrams, could be more effective. Again, having resources that the parent can keep and refer to in the future. Mrs. Smith could have also been given a list of other resources such as websites and phone numbers of accessible providers; going even a step further, she could have been scheduled for a follow-up appointment for Max before leaving the ED.

The ED presents a valuable opportunity to provide education to patients and family members. Improving health literacy in parents who frequently utilize the ED can improve patient satisfaction and reduce the number of potentially avoidable pediatric ED visits. The moral value of the informed consent process should not be diminished to signing a permission slip, but rather should be conducted to promote a truly informed, and autonomous choice. Further research is needed to create readily understood cost-effective educational tools and resources that can be easily widely implemented in the ED course of treatment.

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CURRICULUM VITAE

Education:
BS in Biology, Cum Laude, May 2021- UNIVERSITY OF SOUTH CAROLINA, Columbia, SC
MA in Bioethics, December 2023 - WAKE FORREST UNIVERSITY, Winston-Salem, NC

Professional Experience:
Clinical Studies Coordinator, Wake Forest Institute for Regenerative Medicine, June 2023-Present

- Successfully recruit and enroll over 90% of potential participants for five active clinical studies and trials within the department of Urology and multi-site national clinical organizations.
- Communicate with patients, obtain informed consent, manage study records, interpret data, and schedule appointments with patients and providers for concurrent studies.
- Collaborate with multiple physicians, APPs, and nursing team members to collect tissue samples in the operating room twice a week.
- Effectively communicate with personnel at the FDA (Food and Drug Administration), NIH (National Institutes of Health), IRB (Institutional Review Board), DOD, and the Wake Forest IRB (Institutional Review Board) regarding applications, amendments, and approvals for applicable studies.

Medical Scribe, Emergency Department, RBWJBH Medical Group, August 2021-July 2022

- Documented medical history and physical exam of over 500 patients in the EMR (Electronic Medical Record)
- Organized treatment protocols in a fast-paced emergency room environment
- Reported medical data discrepancies to physicians and APPs
- Assisted physicians in accessing all relevant test results and medical history documents.

Honors and Awards:

Departmental Bioethics Scholarship, 2022

Galen Health Fellow, 2017-2021

- A living and learning community at the University of South Carolina that fosters a transdisciplinary residential environment for undergraduate students pursuing a career in health care. Participated in service learning, mentorships, and beyond-the-classroom experiences.

Dean’s List, Fall 2017, Spring 2020, Fall 2020 And Spring 2021

- Awarded to students who finished the semester with a GPA of 3.5 or higher.

Community Service:

Palmetto Place Children’s Shelter

- Volunteer tutor

Certifications:

Suicide Prevention Gatekeeper, 2020

- Trained in the warning signs of a suicidal person and early signs of depression and how to respond in confidence.

Memberships/ Affiliations:

Alpha Epsilon Delta

- Health pre-professional honors society at the University of South Carolina

Zeta Tau Alpha

- National woman’s fraternity dedicated to raising awareness of breast cancer care, education and prevention