Distribution Agreement

Signature: Dylan P. Hurley. **Date:** 15 JUL 2024

Autism Care Ethics in the Emergency Department: From Triage to Disposition

By

Dylan P. Hurley
B.S., Emory University, 2020
M.P.H., Emory University, 2022
Bioethics

Kathleen Kinlaw, M.Div.
Advisor, Thesis Chair

April R. Dworetz, MD, MPH, MA
Committee Member

Claudia R. Morris, MD, FAAP
Committee Member

Accepted:

Kimberly Jacob Arriola, PhD, MPH

Dean of the James T. Laney School of Graduate Studies

Autism Care Ethics in the Emergency Department: From Triage to Disposition

By

Dylan P. Hurley
B.S., Emory University, 2020
M.P.H., Emory University, 2022

Advisor: Kathleen Kinlaw, M.Div.

An Abstract of

A thesis submitted to the Faculty of the

James T. Laney School of Graduate Studies of Emory University

In partial fulfillment of the requirements for the degree of

Master of Arts

In Bioethics

2024

Abstract

Autism Care Ethics in the Emergency Department: From Triage to Disposition

By Dylan P Hurley

With the increasing prevalence of autism spectrum disorder (ASD), healthcare providers in the pediatric emergency department (PED) must reflect on delivering patient-centered and ethically-informed care. Patients with autism are more likely than their neurotypical peers to utilize the pediatric emergency department for a range of chief complaints, including behavioral health emergencies. Current practice utilizes standard behavioral health protocols to care for patients with autism presenting with aggression and other behavioral health complaints. As a result, the ethics of behavioral healthcare in the PED through department protocols such as venipuncture for medical screening or the use of chemical or physical restraint must be considered.

This work proposes a paradigm shift from current practice to a practice informed by the proposed Autism Care Ethics (ACE). ACE utilizes aspects of care ethics and the growing field of autism ethics to present a lens for ethically informed care of the ASD patient in the PED. ACE attempts to integrate considerations of empathy into practice. Previously proposed elements of an ethics of care such as “context-dependence” and “relationship orientation” are utilized to form a theory of care that is both patient-centered and trauma-informed.

Autism Care Ethics in the Emergency Department: From Triage to Disposition

By

Dylan P. Hurley
B.S., Emory University, 2020
M.P.H., Emory University, 2022

Advisor: Kathleen Kinlaw, M.Div.

A thesis submitted to the Faculty of the

James T. Laney School of Graduate Studies of Emory University

In partial fulfillment of the requirements for the degree of

Master of Arts

In Bioethics

2024

Contents

Introduction: Triage – *Michael's Narrative*

The paramedics entered the emergency department, stretcher in tow, as the door clicked, indicating that the unit clerk nearby has approved their entry. On this paramedic's stretcher is Michael.

Michael is a fourteen-year-old, standing a little over 6 feet tall and weighing in at over 225 pounds. Michael is living with autism spectrum disorder. You wouldn't know his diagnosis without reviewing its extensive documentation. It can be found in his case file with the Department of Family Services, or his Individualized Education Plan (IEP), or the patient alert advisories that flag his electronic medical record indicating his diagnosis and his "aggressive nature." These are just a few areas (social, educational, etc.) of Michael's life where his vulnerabilities should be protected and best understood. Instead, Michael's vulnerabilities are misconstrued, leaving many of his needs unmet.

Michael has long struggled to interact with those around him. He often finds his environment over-stimulating. He struggles to verbally communicate with those around him and did not develop the ability to meaningfully communicate until he was four years old. His family and teachers still rely on pictorial support to communicate his basic wants and needs. As Michael enters the ED, it is evident that he has been physically restrained to the stretcher with four-point soft restraints; the soft, padded cloth secured around both of his wrists and ankles and then to the stretcher. Michael is asleep on the stretcher due to the Versed (midazolam)[1] that was first given to him by the paramedic for his aggressive behavior while refusing to be loaded into the ambulance. Despite the Versed, Michael "put up quite a fight," the paramedic explained over the

---

[1] A benzodiazepine, frequently used to produce sleepiness or drowsiness, often in procedural sedation or anesthesia. In instance, for the indication of severe agitation per EMS protocol (MedlinePlus).

phone in report to the nurse a few minutes earlier. The paramedic administered the Versed, through the intramuscular route (IM) while someone distracted Michael from the needle headed toward his thigh.

His foster mom had called 911, but only because Michael had been grabbing at his stomach all day. She knew that something was not right. Before she could blink, Michael was strapped to a backboard,[2] loaded onto a stretcher, and then onto the ambulance. The paramedics and police officers that responded to her call and then the subsequent back-up call for assistance, told her to meet her son at the local pediatric emergency department, thirty minutes from their house. This was not the first time that this scenario had played out, exactly like this, but she did not know what to do. She knew Michael was in pain and that he needed to see a doctor. Michael did not want to get into the car when she first tried. Still, she knew something was wrong with him. She hesitated to call 911 because she knew what would happen. They would cause him to escalate because they didn't understand that he experienced the world differently.

The charge nurse walked up to the paramedics and completed a quick triage of Michael as he came through the doors.

"This is the behavioral with autism, right?" asked the nurse.

"Yeah, Michael. Y'all should be familiar. Foster mom was right behind us."

The nurse placed the patient ID band on Michael's ankle (where he would be less likely to tear it off) and signaled for them to go to Room 12, where a team was waiting for his arrival. The charge nurse placed orders for a typical behavioral complaint: venipuncture for a complete blood

---

[2] A piece of equipment often used by EMS personnel to stabilize the spine in trauma patients. In this instance, it was used to transport and secure a behavioral health patient.

count, a complete metabolic panel, and two extra tubes of blood (in case they need it), a urinalysis, a one-to-one patient safety sitter, and a consultation with the behavioral health social worker. The nurse triaged Michael an ESI[3] Level 2 (like all behavioral complaints) and typed in the patient's chief complaint:

Pt BIB EMS with agitation. Hx of ASD. Physically and chemically restrained in route.[4]

Michael's case, although fictitious, will provide insight into the experience of patients with autism, as we examine the ethical considerations in the care that he receives in the pediatric emergency department (PED). As a new paradigm, I propose autism care ethics, for healthcare workers to consider while caring for autistic patients[5] in the pediatric ED. We will utilize Michael's case to illustrate its implementation in the clinical setting.

This project will explore ethical considerations of patient-centered and trauma-informed care for children with autism spectrum disorder (ASD) in the acute care setting, particularly in the pediatric emergency department. The paradigm of autism care ethics, set in an ethics of care, should be translated throughout medicine and nursing care for use particularly with vulnerable patient populations and across subspecialities of medicine.

Patients with ASD seek emergency treatment for various chief complaints, not just behavioral. These encounters occur in dedicated pediatric emergency departments (where this project is primarily situated) and in general emergency departments and other treatment areas across hospitals and within doctor's offices.

---

[3] Emergency Severity Index – the system utilized by American emergency departments to triage patients based on acuity and anticipated resource requirement (Gilboy, 2020).

[4] Pt = patient, BIB = "brought in by," Hx = history

[5] Identity-first language (autistic person) will be interspersed throughout this work, in line with the preferences of a segment of the autistic community. Many in the academic community and professionals still use person-first language (person with autism). As a result, both will be utilized (Autism Self Advocacy Network, Taboas 2022).

It is essential that emergency departments deliver effective and appropriate care in an ethically informed manner to meet the needs of vulnerable patient populations, such as those with a diagnosis of ASD. Autism care ethics will provide a lens to view and deliver care in the pediatric emergency department setting. This work will explore considerations of autism care ethics and the need for its implementation to provide ethically appropriate care to autistic children.

Chapter One will provide a brief overview (history & diagnostic criteria) of autism spectrum disorder, provide the most recent ASD prevalence data, and introduce the paradox that exists between our healthcare infrastructure and the autistic child as they seek care in the healthcare system. The chapter will examine the environment of the emergency department and its unique parameters and functionality.

Chapter Two will explore commonly introduced interventions to effectively meet the needs of the autistic patient in the emergency department, highlighting where current practice does not align with ethical principles in patient care. The chapter will also revisit Michael as he begins his emergency department stay and experiences some of these interventions.

Chapter Three will offer a proposal to alter the current paradigm through which healthcare providers care for the autistic child in the pediatric ED and beyond. This discussion will utilize the concept of care and care ethics while exploring its applicability to treating the autistic patient in the ED setting. Michael's case will be used to humanize these considerations through an autism care ethics approach.

Chapter Four will dig deeper into the ethical implications of current approaches to the ASD patient in the emergency department. The chapter will examine how principles of biomedical ethics can complement an ethics of care approach. This chapter will conclude by integrating clinical empathy, and the lack thereof, as a possible source of many of these issues.

Chapter Five will suggest future directions for the use of autism care ethics in the pediatric ED and beyond while revisiting the concept of empathy in care and medical practice. The chapter will conclude by summarizing the main aspects of autism care ethics as they have been applied to ethical considerations in caring for the autistic patient in the pediatric emergency department.

Michael's fictitious case and the inspiration for this project was informed by my experience initially volunteering and then working in and around a pediatric emergency department in Metropolitan Atlanta from 2016-2022, as we experienced a surge in pediatric behavioral health cases.

Chapter 1: History & Physical: Autism Spectrum Disorder & the Emergency Department

What is Autism?

First described by Leo Kanner in 1943 as “a fundamental disorder” in which “the child’s inability to *relate to themselves* in the ordinary way, to people, and situations from the beginning of life,” demonstrates how understandings about autism have transformed over time (Kanner 1943). The National Institute of Mental Health currently defines autism spectrum disorder as, “a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave” (NIMH 2024). While Kanner’s initial description of autism is not much different than currently utilized definitions and criteria, autism today is seen as a spectrum, that can range from extremely mild to severe (Lord 2018).

Work conducted in the late 1970’s and into the early 1980’s by Lorna Wing, put forth the “triad of impairments” that described those children with “autistic tendencies.” The triad included impaired social interactions, impaired verbal & non-verbal communication, and impaired imaginative behavior. These characteristics identified behaviors likely to identify neurodivergent children with the diagnoses of autism and Asperger’s syndrome. These are two diagnoses that have continued to evolve over time aided by research and changing paradigms.

Autism spectrum disorder (ASD) can be found within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which standardizes the criteria upon which qualified professionals make a diagnosis. The DSM-5 transitioned to utilization of the term ASD from common diagnoses of classic autistic disorder, Asperger’s syndrome, and pervasive developmental disorder to account for the spectrum of severity and type of symptoms that individuals experience (NIMH 2024). In addition to the DSM-5, ASD has also been integrated into the International Classification of Diseases, 11th revision (ICD-11), a representation of how ASD has become medicalized and then standardized across medical practice.

The DSM-5 outlines the following criteria for an autism spectrum disorder diagnosis[6]:

A. "Persistent deficits in social communication and social interaction across multiple contexts."
B. "Restricted, repetitive patterns of behavior, interests, or activities, manifesting in at least two of the outlined criteria[7]."
C. "Symptoms must be fully present in the early developmental period."
D. "Symptoms must cause clinically significant impairment in social, occupational, or other areas of current functionality."
E. "Disturbances are not better explained by intellectual disability or global developmental delay."

The DSM-5 outlines additional diagnoses that should now be considered under the ASD umbrella, including; early infantile autism, childhood autism, Kanner's autism, high-functioning autism, atypical autism, and childhood disintegrative disorder (in addition to previously mentioned Asperger's syndrome and pervasive developmental disorder) (American Psychiatric Association).

A diagnosis of autism spectrum disorder should be taken with caution due to its complexity, as the core symptoms outlined by the DSM-5 do not account for the non-specific manifestations in different ages and differences in individual abilities in intelligence and verbal domains (Park, 2016). This warning is a result of the individualistic nature (what will later be

---

[6] Criteria obtained directly form the Diagnostic and Statistical Manual of Mental Disorders (DSM-5).
[7] See the DSM-5 for complete criteria. Full criteria not necessitated for this purpose.

referred to in this work as autism's heterogeneity) of ASD that providers should consider when diagnosing and caring for the ASD patient across medical settings. In this particular work, we will explore ASD in the pediatric ED.

Autism Spectrum Disorder by the Numbers

The Center for Disease Control and Prevention's (CDC) 24 March 2023 edition of the Morbidity and Mortality Weekly Report (MMWR) detailed new statistics on the status of autism spectrum disorder in the United States. The MMWR report examined data from the eleven Autism and Developmental Disabilities Monitoring (ADDM) sites nationwide. The data revealed an increased prevalence of ASD in the United States, from 1 in 44 in 2018, to 1 in 36 in 2020. This increased prevalence is reason to ensure that ethical considerations of the autistic community and ethically appropriate care within the healthcare system be delivered effectively.

The prevalence of ASD was found to be higher amongst non-Hispanic Black or African American (Black), Hispanic, and non-Hispanic Asian or Pacific Islanders for the first time, likely a result of increased participation in screening and education efforts. It is thought that the increased prevalence can be attributed to "improved screening, awareness, and access to services amongst historically underserved groups." (Maenner 2023). Of note, Black children with ASD were more likely to have co-occurring intellectual disability than White children, which has been observed through multiple ADDM surveillance reports. ASD was 3.8 times more prevalent in males than females. For the first time, the overall prevalence for females was >1%, which may also be a result of an increase of screening and awareness.

The Autism Spectrum Disorder & Healthcare System Paradox

Patients with ASD have significantly higher rates of healthcare utilization (Iannuzzi, 2015). Autistic children use emergency departments for care more than pediatricians' offices. Children with ASD are 9 times more likely to receive care in the emergency department than those children without an ASD diagnosis (Kalb, 2012). This frequency supports the need for emergency departments (both in dedicated pediatric EDs & adult EDs) to be equipped to meet the individual needs of the patient with ASD.

One can infer that ASD patients utilize healthcare resources at a greater rate due to the increased rates of comorbidities among the population. Numerous studies have shown that children with ASD have higher rates of epilepsy, respiratory illness, sleep disorders, gastrointestinal disorders, food & skin allergies, and anxiety & depression (Iannuzzi, 2015). In examining epilepsy, Tuchman claims the risk of children with ASD to be diagnosed with epilepsy to be as high as 33%, with diagnoses peaking prior to the age of five and just as children enter puberty (2002). Epilepsy and respiratory disorders present a potential increased need for utilization of acute care resources that emergency departments and pediatric intensive care units offer. As a result, resource allocation becomes an important consideration of care for the ASD population both within the behavioral health setting and in other specialized care areas of the hospital[8].

While children with ASD exhibit behaviors that are more difficult for clinical professionals to accommodate, especially in over-stimulating environments such as a busy emergency department, it is important that providers do not attribute behaviors solely to overstimulation or communication barriers. These behaviors have been found to be strongly

---

[8] Mental and behavioral health resources are usually associated with other clinical care reosurces in a health system. For instance, in emergency departments, 1:1 patient sitters often hold other roles in the department when there are not behavioral health patients.

associated with diagnosable physical and mental health disorders which can be ascertained through a proper physical examination and indicated diagnostic work-up (Isaksen, 2013). This reinforces the need for emergency providers to commit to extensive history taking and thorough physical examination of all patients presenting with a history of ASD. It is ethically concerning that diagnosable physical and mental health conditions may go overlooked due to generalizations made regarding patient behaviors or differences. These perceptions allow for biases to overshadow what could other be otherwise undiagnosed medical conditions.

McGonigle compares the patient with ASD presenting in behavioral distress to an iceberg (2014).

> **"The challenge is for emergency medicine personnel to systematically gather the key information necessary to address the issues that may be underlying or contributing to the 'tip of the iceberg' crisis behavior presentation of patients with ASD" (McGonigle, 2014)**

The "tip of the iceberg" refers to the agitated state in which the autistic patient presents to the emergency department. However, utilizing McGonigle's analogy, there may be an underlying medical cause beneath the water's surface that is not readily visible. In this case, the emergency personnel caring for the patient may need to further examine the patient to determine what is "below the surface". The iceberg analogy presents a situation where a provider's approach to caring for a patient is not directed at the entire issue at hand. As a result, the underlying issue (the iceberg under the water) goes unnoticed.

The increased rate at which children with ASD utilize healthcare and the mismatch between provider assumptions regarding autistic children, present a paradox which highlights the need for ethical consideration as it relates to resource allocation and health system preparedness to meet the individual needs of the autistic patient.

The Current Status of Behavioral Health in the Pediatric Emergency Department

In the emergency department setting, patient with autism presenting with behavioral disturbances are often grouped with behavioral and mental health complaints. Over the past two decades, the behavioral health needs of pediatric patients (both with and without ASD) have grown exponentially. Most emergency departments are not equipped to handle this growth, although the emergency department continues to function as a default location for behavioral healthcare for children and adolescents (Stricker 2018). In fact, the emergency department remains the only setting in which a screening exam for a psychiatric emergency must be offered and is guaranteed, due to the enforcement of the Emergency Medical Treatment and Active Labor Act (EMTALA) of 1985 (Dolan 2011). As a result, patients routinely present to the emergency department with suicidal ideations, aggressive and homicidal behaviors, and psychosis (Nadler 2021). Behavioral health patients in the emergency department have a higher average length of stay and higher rates of admission than those seeking care in the ED without a behavioral health complaint (Santiago 2006). This results in ethical questions regarding longer boarding times and the potential for disproportionate treatment relative to other ED populations which may directly result in care disparities.

Emergency departments that have department-oriented goals related to total length of stay and "turn-around" times[9] are often presented with a problem due to the increased length of stay experiences by the mental and behavioral health populations. Children and adolescents in behavioral crisis are presenting to emergency departments for care in unprecedented numbers. These patients are then staying in the department longer (due to overcrowding and limited

---

[9] The total time from patient arrival to disposition for an emergency department stay. Often a parameter used for department efficiency.

resources). As a result, they are admitted at greater rates for inpatient psychiatric care (Nadler 2021). Inpatient psychiatric care is not often available in the pediatric hospital or even adult hospital in which the patient presented. Often, this results in many behavioral health patients being transferred to tertiary behavioral health centers. Ethical concerns related to delays in admission to inpatient treatment combined with the appropriate allocation of resources to vulnerable populations are important considerations in this area of behavioral healthcare in the emergency department and beyond.

Patients seeking care for behavioral health in the pediatric emergency department are staying longer (entering boarding status) compared to other children with non-behavioral chief complaints (Nadler 2021). Nadler also found that there was a significant increase in total time spent in the pediatric ED for these patients, presenting the issue of increased times to disposition and increased time to inpatient psychiatric admission (2021). Likewise, Wharff estimated that 34% of pediatric behavioral health patients were boarded in the emergency department awaiting inpatient psychiatric placement after a disposition (2011). This has resulted in overcrowded pediatric EDs and has placed a significant strain on mental and behavioral health resources.

In 2009, data aggregated from sites affiliated with the Pediatric Emergency Care Applied Research Network (PECARN), found that psychiatric or behavioral complaints accounted for 3.3% of total pediatric ED visits at affiliated centers compared to the 1.6% prevalence rate previously published by Sills & Blanchard in 2002 (Mahajan, 2009). In the decade since prevalence was examined by Mahajan and the PECARN Registry Working Group, the percentage of children requiring emergency psychiatric evaluations had doubled in a retrospective review of pediatric emergency encounters in 2004 compared to in 2014 (Nadler

2021). This demonstrates the continued exponential growth in pediatric behavioral health cases that is taking a toll on emergency department resources across the country.

An additional challenge exists when hospitals do not have inpatient psychiatric units. In 2016, Sheridan examined trends in emergency department care for a pediatric tertiary hospital with no associated inpatient psychiatric unit; meaning that all patients requiring further psychiatric care must be transferred to an accepting outside facility. The study found an 11.1 hour increase in length of stay times for behavioral health patients pending admission; an increase from 6.7 hours in 2009 to 20.8 hours in 2013. A single patient even accumulated a total stay of 337.2 hours (Sheridan, 2016). With limited options for transfer to inpatient psychiatric care, providers are also left to consider other factors such as insurance status and parental consent for transfer. The aspects of which factor into the ease of the transfer process and leave pediatric behavioral health patients without dedicated and targeted psychiatric care for days at a time. As a result, the emergency department becomes a “boarding house” for those seeking psychiatric care that far exceeds its capabilities.

Patients requiring emergency psychiatric evaluations in the emergency department are more likely to be transported by EMS as opposed to personal vehicle, which was consistent with Mahajan’s findings in 2009 (Nadler 2021). Pediatric and adolescent psychiatric emergencies rely on EMS for initial pre-hospital response and care for these emergencies. They also depend on EMS systems for subsequent transport to emergency departments. Thus, EMS providers have become a key component of the behavioral health response within our current healthcare infrastructure. Many healthcare professionals are involved in treating behavioral health emergencies and as a result must be better equipped to meet the needs of behavioral health patients (including those with ASD) in an ethically appropriate and patient-centered manner.

What Happens When a Patient Presents for a Behavioral Complaint?

In September 2023, a technical report released by the American Academy of Pediatrics, outlined recommendations for how behavioral healthcare should be rendered in the pediatric emergency department (Saidinejad 2023). The report recommended that the triage of patients presenting to the emergency department with behavioral health complaints to be assigned an Emergency Severity Index (ESI) Level 2. This is due to the elevated risk of self-harm or violence toward themselves or others (see Figure 1). In accordance with protocols in the operations manual of the Centers for Medicare and Medicaid Services (CMS), a one-to-one safety sitter is necessary to ensure patient safety. Safety sitters are utilized in patients with a risk of elopement, self-harm, violence, or aggression (DHHS CMS Operations Manual 2017). Patient safety sitters represent another group within the interdisciplinary healthcare team that may benefit from an ethically informed lens for caring for the ASD patient due to their proximity to their patients.

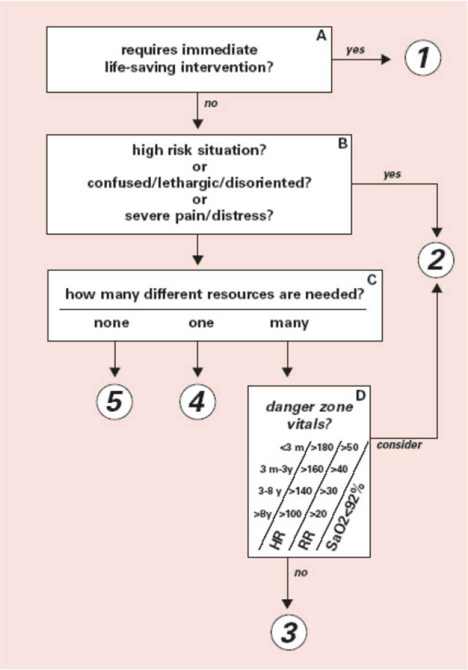

Figure 1: Emergency Severity Index, Triage Algorithm (v4), adapted from Aacharya et al. (2011)

In ensuring environmental safety, a safety check of the patient and the patient's environment is recommended to ensure any weapons or objects that may result in self-harm or injury to others are removed from the patient's environment (APNA 2020). A technical report from the American Psychiatric Nurses Association recommends 1) safe emergency department spaces with decreased safety hazards and risks and 2) safety checklists to promote safe environments (2020). Recommendations include the removal of sharps containers, any medical equipment that is not secure to room walls, and items such as unnecessary chairs and trash cans (Saidinejad, 2023). As a result, many emergency departments have adopted dedicated spaces for the screening, evaluation, and management of behavioral health patients (Mroczkowski, 2018). This may feature convertible patient rooms with garage doors that may be moved up and down to conceal any clinical medical equipment from the patient's reach. The "behavioral safe" room may not be as inviting and welcoming as other pediatric ED exam rooms resulting in ethical questions related to the modifications of patient's environments, especially when coupled with the extended length of stay that some behavioral health patients experience.

The American Academy of Pediatrics recommends that providers obtain a thorough history and physical exam once a patient is placed in a safe environment (Saidinejad 2023). The AAP cautions against unnecessary laboratory and diagnostic tests (Donofrio, 2014). The patient and their caregiver should be interviewed together and separately (for confidentiality) during mental health assessments. While providers should be concerned with typical presentations and differential diagnoses of psychiatric conditions, they should also be concerned with potential somatic medical conditions that can accompany behavioral symptoms which aligns well with McGonigle's iceberg analogy mentioned earlier (Saidinejad, 2023).

Patients are typically evaluated by the emergency department provider in addition to being evaluated by a qualified mental health professional (psychiatric social worker, psychiatrist, psychologists) depending on the specific infrastructure of the health system (Caffy, 2019). During this process, temporary psychiatric holds by a licensed and qualified provider may be deemed necessary for the patient in accordance with state law. At the same time, the emergency provider typically works to provide medical clearance, so that a disposition can be made to inpatient psychiatric care if appropriate. Concern has been raised in pediatric behavioral health regarding how often involuntary psychiatric holds are utilized and whether the least restrictive alternatives are being bypassed. With patient safety at the forefront of this discussion, it does uncover potentially critical ethical implications related to current practice (Santillanes 2020, Chun 2016).

The medical clearance process that the emergency provider conducts has three main objectives (Saidinejad 2023):

1) "To assess for somatic medical processes that are causing the psychiatric complaint (ex. Endocrine disorders)"
2) "To treat any illness or injury related to the acute behavioral health emergency (ex. A laceration from self-harm)"
3) "To adequately stabilize chronic somatic medical conditions prior to the psychiatric evaluation (ex. diabetes or asthma)"

As a result, ensuring that a patient may be "clear" of all potential acute or exacerbated chronic co-morbidities can become a time consuming and daunting task. Often, patients remain in holding for days waiting for slightly abnormal laboratory results to normalize, which would have otherwise not required treatment. The American Academy of Pediatrics technical report, utilizes the term “medical optimization” of the patient to better label this process, acknowledging that complete resolution of some issues may not be necessary or even feasible without significantly delaying further inpatient psychiatric treatment or discharge (Saidinejad, 2023).

After medical clearance, psychiatric evaluation, and brief acute interventions, the emergency provider determines the final disposition for the patient. The patient is either discharged home or admitted for inpatient psychiatric care, if deemed necessary. It is important to highlight that not all emergency departments are in hospitals with dedicated psychiatric inpatient care (Sheridan 2016). As a result, patients are often transferred to psychiatric units for further care. In a review of the Nationwide Emergency Department Sample (NEDS), from 2007 to 2016, there was a 137% increase in patients having to be transferred to outside facilities for further dedicated psychiatric care (Lo, 2020). In a review of 35 freestanding children’s hospitals, only 14 (40%) had a dedicated inpatient psychiatric unit (IPU) in which they could admit patients directly from their emergency department (Cutler, 2019). This depicts how a lack of resources directly contributed to delays in patient care and likely patient outcomes.

As previously discussed, emergency departments have noticed a significant increase in length of stay and prolonged boarding status after disposition. As a result, these considerations must be at the forefront of the development of a paradigm that can effectively support autistic patients (who may require more or specialized resources) while taking into consideration the current limitations of the emergency department and psychiatric health care system.

ASD in the Emergency Department

The emergency department presents a unique setting for the care of the patient with autistic patient when presenting with a behavioral complaint. Patients with ASD that present with agitation or behavioral outburst are often grouped with and proceed through the same emergency department protocols as other behavioral health patients in the department. In addition to this association, the dynamic nature of the ED presents the issue of over-stimulation and unpredictability. McGonigle highlights the goal of emergency providers treating patients with ASD, by outlining that providers must "rapidly assess and optimize effective treatment in the least restrictive manner" (2014). This goal often presents a challenge as the emergency department is fast paced with competing priorities and limited resources. As a result, the behavioral health patient not in immediate crisis may not receive the immediate resources and examination that a trauma patient or severely ill patient may receive. For patients with ASD, this may result in significant delays to therapeutic resources or a lack of understanding of the care team that the patient's needs may be different than those of other behavioral health patients.

A key obstacle to treatment of the patient with ASD in the emergency department is recurrent unfamiliarity. Patients are often unfamiliar with their environment and the people that care for them (Straus 2019). Variable shift staffing, floating roles, and a large and often chaotic environment are all factors at play in the unfamiliarity and inconsistency that exists in the emergency department. These factors may create a barrier to effectively care for the autistic child in the ED setting. Other aspects of the ED such as the bright fluorescent lighting, excessive noise, an abundance of staff, and potentially lengthy wait times impact the acute care environment and the ability of children with ASD to cope and adapt to the environment (Straus 2019). In all, EDs are not entirely welcoming environments for autistic patients. However, many of these factors can be taken into consideration in the care plan through an ethically grounded approach.

In accordance with the paradox that exists between the healthcare system and the care needs of patients with ASD, one of the main obstacles that pediatric emergency medicine providers face is that preverbal and nonverbal patients are often unable to express ailments or feelings through words. As a result, patients may cry or have emotional or aggressive behaviors. Eldridge offers, “crying due to pain is often difficult to distinguish from anxiety” (2010), effectively outlining the struggle that pediatric providers face in the emergency setting in interpreting patient behaviors as it relates to pain or discomfort. These difficulties can be related back to McGonigle’s “tip of the iceberg” theory, as patients with ASD often have communicative limitations which restrict their ability to communicate with their healthcare team.

The waiting room of the emergency department presents a particularly distressful environment for children with ASD. Straus states that upon a review of twelve articles considering the psychosocial impact of the waiting room environment on children with ASD, it was evident that “lengthy wait times were a catalyst for agitation” (2019). Autistic patients may arrive at emergency departments via ambulance or personal vehicle. In both instances the potential for a wait time can lead to agitation throughout the ED stay. Emergency departments may not have a room readily available upon patient arrival or standard department protocols could lead to delays in placing a patient in a room, as “behavioral safeguards” [10] must be put in place prior to a patient entering the room. Here, the mismatch between the needs of the autistic patient and the capabilities of the pediatric ED may further escalate patients leading to ethical questions surrounding non-maleficence.

---

[10] See “The Current Status of Behavioral Health in the Pediatric Emergency Department” for more information regarding standard of care practices.

Later chapters will describe further interventions currently used to care for patients with ASD in the emergency department. It is important and ethically necessary that care decisions and protocols that are being implemented in both the pediatric and adult emergency department settings remain tailored to the individual needs of each patient and optimize treatment for the patient in the least restrictive manner. These protocols should aim to ensure patient safety while prevent any potential harm and further escalation.

Other Factors at Play in the Emergency Department

The emergency department is an unpredictable and rapidly changing environment with factors that impact many of the aspects of acute behavioral healthcare and care for the autistic patient. Many have been discussed in this chapter. In this context, it is imperative to further consider factors concerning the functionality of emergency departments that impact provision of care.

Nursing and physician burnout rates are at an all-time high. Emergency medicine physicians faced the highest reported burnout rates compared to their physician peers in other specialties (Chang 2018). In emergency nursing, the estimated burnout rate is 31%, much higher than rates reported in other nursing specialties (McDermid 2020). Interestingly, both studies were conducted prior to the COVID-19 pandemic, which placed more stress on the already fractured emergency department workforce. Due to higher burnout rates, in emergency departments (both pediatric and adult) and resultant poorly staffed departments, staff to patient ratios for higher acuity patients is often inadequate (Glatter 2023). This leads to an incongruity between available resources and the resources that are required to effectively treat patients.

A cornerstone of emergency medicine is the allocation of resources and competing priorities. Aspects such as the triage of patients, as previously discussed (ESI Triage Algorithm), help emergency providers to determine who is the "sickest" and who might require the most resources from the department for effective treatment. With high department volumes, it is common for there to be multiple patients deemed the "sickest" and resources must be allocated accordingly (Funderburke 2008). With emergency department overcrowding, resource allocation becomes an important aspect of an efficient and effective department due to the limited number of resources available in emergency staff, space, and treatment equipment (Aacharya 2011). As a result, behavioral mental health patients may struggle to retain resources, especially during long periods of boarding when the patient may otherwise be deemed stable. For example, an emergency department during the overnight will likely be running with limited staff. A patient care technician may be sitting 1:1 with an ASD patient when a cardiac arrest comes into the department. The medical emergency needs resources (the ED tech, for chest compressions) but they are sitting with the patient. In this situation, department management finds themselves in a situation where they must allocate resources accordingly. However, there are only so many people staffed in the ED. In this situation does a patient's safety supersede the need for life-sustaining treatment of another patient? These are the ethical considerations that must be made when exploring resource allocation in the emergency department.

Healthcare workers in the emergency department are at an increased risk of workplace violence (Boles 2023). In the emergency department setting, there is a risk of exposure to patients that may be agitated or with an altered mental status leading to potential physical violence and/or verbal threats (Aljohani 2021). These risks extend to the pediatric emergency department, where there are even more considerations for healthcare teams to take into account, including the involvement of parents and/or caregivers. When looking at how to best care for behavioral health patients in the emergency department, it is important to prioritize safety for both the patient and the healthcare worker. As a result, protocols may be geared toward chemical and physical restraint to promote the safety of the healthcare worker and the patient. However, this may not always be implemented in an ethically informed manner that considers aspects such as autonomy and the least restrictive alternative, which we will explore later in this work.

Staff turnover due to burnout and the associated staffing issues, the proper allocation of limited resources, and potential workplace dangers are all aspects of emergency medicine that play critical roles when developing protocols for the treatment of behavioral health patients and patients presenting with ASD. It is important that these aspects of emergency medicine be considered in the development of an ethical framework for care of the autistic patient in the ED. It is also pertinent to understand the current status of ED care for behavioral patients and autistic patient in pediatric and adult emergency departments across the country.

Chapter 2: The Work-Up: What We Do Currently

Dedicated pediatric emergency departments as well as adult emergency departments struggle to meet the needs of the autistic patient. Although these patients often present for behavioral health related concerns, they can present for other medical concerns. This chapter will explore current approaches of clinical teams in emergency medicine to the treatment of autistic patients presenting to the emergency department. The chapter will explore the integration of autistic patients into the behavioral health population, the use of unnecessary diagnostics for these populations, coping plans, de-escalation and restraint use, admission to inpatient units, as well as training for healthcare providers. The discussion will include more of Michael's narrative in order to understand aspects of the delivery of care to the patient with ASD.

Association of ASD Patients with Behavioral Health Patient Populations

When a patient with an ASD diagnosis presents to the Pediatric ED with self-injurious behavior or aggression, responding with a behavioral health protocol may be inadequate. While the patient may necessitate some aspects of the behavioral health protocol (a safe environment, a patient safety sitter, etc.), the protocol may fall short of the patient's needs as this behavior may be a manifestation of underlying medical conditions. Often, signs and symptoms of these medical conditions can be diagnosed through physical examination. It should be ethically concerning to providers and advocates within the ASD community that potential medical concerns may be overlooked and explained as a manifestation of the patient's behavior relating to their ASD diagnosis. Iannuzzi explains this well in a report on the status of emergency department utilization by individuals with autism.

“It is important that clinicians not immediately assume that self-injurious or aggressive behavior exhibited by an autistic individual presenting to the ED is primarily a psychiatric or behavioral disorder without first investigating the possibility that a medical condition may be the root cause of aberrant behaviors” (Iannuzzi 2015)

The automatic presumption of self-injurious or aggressive behavior can overlook potential medical causes that are triggering behavioral outbursts. It is important to highlight that children with ASD are more likely to have psychiatric comorbidities than those without an ASD diagnosis. In a 2007 study, 80% of ASD patients reviewed had at least 1 co-morbid psychiatric disorder (de Bruin 2007). A later study estimated that 70% of ASD patients had at least one co-morbid psychiatric disorder and at least 40% had two or more (DeFillipis 2018). Examples of common psychiatric comorbidities include mood disorders, depressive disorders, bipolar disorders, attention deficit hyperactivity disorder (ADHD), anxiety disorders, disruptive behavior disorders, tic disorders & Tourette syndrome, feeding & eating disorders, obsessive compulsive disorder, and personality disorders (Hossain 2020, Mazzone 2016, Lai 2019). There is also a recognized higher rate of suicidality and decreased perceived quality of life among patients with autism (Costa 2020, Oakley 2021, O’Halloran 2022). Given these statistics, it may be evident why providers are quick to associate autism with behavioral health patients. However, this may be leading to more harm than good in the autistic population.

While particular attention should be given to autistic patients presenting to the emergency department with self-harm behaviors or aggression, it is important that the medical team recognize the patient’s behaviors in the context of their ASD diagnosis. If a patient is not immediately exhibiting self-harm behaviors, optimization of emergency department treatment with the least restrictive alternative is warranted. We will examine the ethical grounding for the least restrictive alternative approach in this instance in a later chapter.

There are significant ethical implications in the disregard of potential underlying medical conditions leading to manifestations of aggressive behaviors in autistic patients. It is important for providers to consider the ethical principle of justice when treating these patients. In this case, ensuring that ASD patients are given equitable treatment to their neurotypical peers. While ensuring that a patient remains safe throughout the emergency department stay (which may necessitate behavioral health protocols to prevent self-harm such as, i.e., one-to-one sitters, environmental safety sweeps), it is important that providers attempt to recognize any potential biases that an ASD diagnosis may cause in their assessment of the patient. It is important that providers consider potential medical causes of behavior, just as they would if a patient did not have an ASD diagnosis.

Unnecessary Diagnostics in the Emergency Department

Emergency departments often develop behavioral health nurse-initiated protocols (NIP) that can be ordered directly by nursing staff prior to the provider examination of the patient. This is conducted through standing orders or protocol-based care pathways. It has been previously used in analgesics, anti-emetics, and simple diagnostics such as x-rays (Sampson 2014). NIPs in behavioral health in the pediatric emergency departments, begin the basic behavioral health work-up. This includes blood and urine specimen collection and psychiatric consult prior to physician evaluation. Caregiver or nurse-initiated protocols have been shown to improve delays in the delivery of care and have led to increases in patient satisfaction when used in the emergency department setting (Burgess 2017). However, in the case of the autistic patient, this often results in unnecessary diagnostics and a bias toward selecting a behavioral health complaint. Screening mechanisms such as the Ask Suicide-Screening Questionnaire (ASQ) are utilized to determine risk stratification of self-harm and aggression (Horowitz 2012). They also help to inform care teams of potential resource allocation needs for behavioral health patients. These screening tools may fall short for the patient presenting with ASD, especially if they have a different communicative baseline than their neurotypical peers. As a result, this may result in further bias and the subsequent selection of a behavioral health chief complaint.

Venipuncture for blood collection and urinalysis are components of the behavioral health work-up for all patients presenting with a behavioral complaint. These routine "screenings" have only been shown to impact management of the patient in the emergency department setting for 5-6% of patients (Donofrio 2014). Furthermore, they have only been shown to impact the patient's final disposition in 1% of patients presenting to the emergency department with behavioral health complaints (Donofrio 2014). As a result, invasive diagnostics should only be performed if indicated by an exam finding or previous medical history and not solely for screening purposes. The American Academy of Pediatrics acknowledges that this routine testing has limited utility. Although, screening labs remain a part of many NIPs throughout pediatric emergency departments (Saidenijad 2023). This may be a result of hesitancy to alter perspectives on medical clearance. It also may be attributed to requirements by outside facilities that dictate aspects of "clearance" instead of the treating physician in the emergency department. Many psychiatric facilities will not accept a patient for transfer until they are deemed medically stable according to the accepting facility which results in significant variance between accepting facilities and standards of practice.

In a retrospective chart review examining the clinical significance of venipuncture via nurse-initiated protocol for autistic patients presenting with behavioral complaints, approximately 1% of these laboratory draws resulted in a clinically significant result (Hurley

Forthcoming). Nurse-initiated protocols as well as facility preference for “medical clearance” force many of these lab draws to take place prior to physician examination and assessment.

As a result, ASD patients are subjected to adverse experiences (in addition to occasional physical and chemical restraint) in an attempt to collect laboratory specimens that have no clinical significance or impact on disposition. There have been calls to end the practice of screening labs for “medical clearance” for all behavioral health patients in the emergency department, including in the American Academy of Pediatrics’ recent “*Choosing Wisely Campaign*” from the Pediatric Emergency Medicine Special Interest Group (PEM SIG) (Chun 2014, Mullen 2024). Unnecessary medical screening for patients with autism in the emergency department is just one of the examples of unnecessary and wasteful diagnostic practices occurring in acute care settings across the country for vulnerable populations.

“Coping Plans” in the Electronic Medical Record

With documented use in surgical and outpatient settings, the “coping plan” has appeared in the pediatric emergency department. It is used primarily with ASD patients and patients with developmental delays. A coping plan is defined as “a formalized summary aimed at helping healthcare providers to deliver individualized care with the purpose of decreasing the anxieties of the child and patient during treatment” (Wittling 2018). The coping plan outlines the specific needs of the patient in many aspects of their hospitalization. It allows the medical team to make adaptations to lessen potential stressors in the environment (i.e., lighting) and in treatment and care plans (i.e., medication administration).

Programs have found remarkable success in partnering with Certified Child Life Specialists (CCLS) for the development of coping plans. In the case of Wittling's 2018 work, they focused on key questions where adaptations could be made in the care plan including:

(a) "In your child's past healthcare experiences, are there any fears or things he/she may have difficulty cooperating with that you have identified?"
(b) "How does your child prefer to take medication?"
(c) "What are some things that may be stressful to your child in our setting (i.e., wait time, putting on a gown or ID band, NPO status, etc.)?"
(d) "What have you found to be calming for your child (i.e., favorite toy, weighted blanket, music, etc.)?"
(e) "What are motivators for your child?"

Questions like these allow the CCLS to ask targeted questions related to triggers in the care environment and preference. They also help to identify potential de-escalation or calming techniques. The coping plan once created, is then integrated into the electronic medical record for the patient. All clinicians entering the patient's chart are prompted with a best practice advisory alert to review the coping plan (Wittling 2018).

Coping plans hold potential value in the emergency department setting in caring for the individual needs of the pediatric autistic patient. Coping plans are an extension of the principle of patient autonomy. Particularly, empowering those who cannot communicate or express their wishes or care preferences due to communicative or expressive deficiencies. The coping plan provides caregivers with a role in advocating on behalf of the patient. The coping plan provides a fantastic avenue for considerations of individual needs of the autistic patient. It is also a resource for patient empowerment and caregiver advocacy.

De-escalation Techniques & Restraint Use

De-escalation techniques for agitated and self-harming patients often comprise physical and chemical restraints. [11] Restraints have been defined as “any intervention used to restrict freedom of movement, physical activity, or normal access to one’s body,” (Joint Commission 2000). It is estimated that 6-8% of pediatric behavioral health patients require some form of restraint (Dorfman 2004 & 2006). Multiple studies have found therapeutic holding techniques to be more beneficial than physical soft restraints, etc. (Miller 1989). Additionally, the most preferred method of physical restraint was in the “supine” position[12] versus “prone” as it is preferrable due to anatomical positioning and safety. However, patients were more likely to calm more quickly in the prone position (Aschen 1995). Outside of these works, very little has been explored in physical restraint use in the pediatric ED. The lack of research in restraint is disproportionate, considering its potentially increased use as a result of the increase in behavioral and mental health patients in emergency departments (Radhakrishnan 2022, Leeb 2020).

There is much debate about the use of chemical restraint in behavioral health emergencies, especially amongst patients with ASD. Much of the concern with autistic patients is related to adverse drug events (ADEs). ADEs due to commonly used medications that treat agitation occur more frequently amongst those with ASD (Gerson 2019). Dorfman (2004) found that the most used agents for chemical restraint were benzodiazepines (e.g., Versed) and butyrophenones (e.g. Haldol). The risk of ADE, although identified, has not been further explored to prevent continued or prolonged chemical restraint. As a result, these drugs are still used to restrain behavioral health patients, especially those presenting with aggression or self-

---

[11] Chemical restraint is no longer the preferred term by the American Psychiatric Association (APA). The group prefers utilization of the phrase “drug used as a restraint.”

[12] Supine (lying face up), Prone (lying face down)

harm. The ethical impacts of chemical restraint cannot go overlooked, especially in the ASD population.

Admission to Inpatient Units (General Pediatrics & PICU)

Patients with ASD can be admitted from the emergency department to inpatient units of the hospital including general pediatrics floors, the pediatric intensive care unit, and inpatient psychiatric units. These settings each offer their own unique environment with different potential triggers for agitation and escalation. Patients with ASD have been shown to be at an increased risk for agitation during admission (Hazen 2020). Much like the emergency department, similar tactics may be employed for de-escalation across hospital settings. However, it is important that healthcare professionals integrate continuity of methods employed throughout different locations in the healthcare system. Such stability will lessen the problems associated with recurrent unfamiliarity (Foster 2023). Health systems have started implementing behavioral emergency response teams (BERT) that respond to behavioral health emergencies in the hospital with standardized de-escalation protocols (Zicko 2017). These teams received specialized de-escalation training and serve as a resource for the entire facility. BERT initiatives are an example of how care teams are identifying problems within behavioral health and are working to address them with specialized and patient-centered care. It is essential that BERT implemented in the pediatric hospital setting are informed regarding the best practice de-escalation techniques for autism.

Thom (2020) offered a review of current best practices for pediatric hospitalists as they admit patients with ASD to the general pediatrics floors from the emergency department for further care. One of the common recommendations is the review and collection of information at admission regarding patient intellectual ability, functional ability, preferred communication style, sensory needs, triggers, and methods to resolve escalation (Scarpinato 2010). Much like with the use of a coping plan in the emergency department, the use of parental questionnaires and care plans have proven to be beneficial in the inpatient setting (Kairys 2016). Utilizing the patient's medical history and a coping plan alongside caregiver input, escalation from changes in the care environment may be prevented.

The most frequently highlighted considerations in the inpatient setting revolved around patient communication and expression. In a review of ASD admissions to a general pediatrics unit, 38% of patients communicated through sign language or gestures, 31% through communication tools, and only 19% through spoken language (Kopecky 2013). It is critical that inpatient units integrate the use of communication toolkits (Hazen 2013) and visual communication systems (Vaz 2013) to effectively communicate with patients. Within the inpatient setting, simple interventions to promote a calm environment such as natural lighting, a private room, clustering nursing care, and closing the door to the room can all be effective in minimizing sensory input that can potentially escalate an autistic patient (Kopecky 2013, Sakai 2014). Again, the patient's environment poses an important area of consideration given the impact of overstimulation and the need for balance between patient safety and patient comfort. The ethical impacts of the tradeoffs between these two facets of the patient experience should be strongly considered.

While there is less literature on caring for ASD patients in the critical care environment, a case study proved particularly interesting regarding an adolescent patient admitted to the pediatric intensive care unit with status epilepticus (Bidner 2007). The team noted the importance of family-centered care, utilizing the parents of the patient to aid in treatment decisions and the overall care plan. Particularly, the team found utility in the parental knowledge of behaviors and triggers. The team worked to minimize potential alarms and unneeded interventions and worked to maintain a quiet room for the patient (an example of environmental modulation). Of note, the patient was intubated in the PICU and remained sedated throughout the PICU stay on a propofol drip (the ethical implications of prolonged sedation and chemical restraint will be discussed in later chapters). The patient remained on sedation up until discharge from the hospital (the case study mentioned utilizing an emergency department room near the exit on the last day of the patients nine day stay) so that sedation could be weaned. The patient then could be transported home by personal vehicle without disruption. This case study provided an insight into how the autistic patient can be treated during a critical care stay. Providers expressed consistent concern for the potential impact of escalation and disruption. Both of which were significant in the development of the care plan. In this case, it was evident that the care team weighed strongly, the impact of patient behaviors on the ICU environment. The patient's prolonged sedation indicates a potential fear of the care team that the patient may have created significant disruptions to the ICU environment. Are these disruptions significant enough to chance the potential risks of prolonged sedation? Additionally, are there ethical impacts of restriction of the patient's autonomy for such a long period of time? These are a few ethical considerations that the case study uncovers within the critical care environment.

It is evident in the inpatient setting in both the general pediatric floors as well as in the critical care, that there are many similar considerations as in the emergency department. However, the readiness of inpatient units to effectively care for patients with ASD does not seem to be as systematic as care in the emergency department. This may be due to the low frequency of cases (especially in the case of the PICU). However, pediatric health systems should work to effectively prepare their teams to care for the ASD population in the inpatient setting in an effective and ethically conscious manner. Efforts should be made to educate care teams on ethically appropriate care for autistic patients. Policies and training should be put in place to establish foundational understandings of ASD. Moreover, these trainings should educate providers on how they can best shape the hospital experience for a patient who may have a different experience due to an ASD diagnosis.

Training for Emergency Care Providers & First Responders

McGonigle highlighted the minimal literature regarding best practices for caring for autistic patients in the pre-hospital or emergency department setting (2013). They revealed that there is no known didactic or practical training for healthcare providers in an emergency department setting for this population. Realizing the gap that exists for pre-hospital providers, the Autism Society developed the *Safe & Sound Initiative* in 2005 to create training materials for first responders on how to best interact, communicate, and treat patients with ASD (Autism Society 2013).

There is an identified need for the further training of staff in the emergency department and in the pre-hospital setting. Most staff are ill-equipped to communicate with and effectively treat patients with ASD. It is important that these groups be provided with training materials and the necessary resources to care for this vulnerable population.

Check-In with Michael

Michael was taken by the paramedics (still restrained on the backboard and then the stretcher) to Room 12, just like the nurse announced over the echoing loudspeaker that made Michael's ears hurt. The bright light in the ceiling hurt his eyes and the loud repetitive beeps from about every room that he passed annoyed him. Four people descended upon him in his room. While one paramedic spoke with his nurse, the rest of the staff picked him off one stretcher and moved him to another. None of them introduced themselves, they just moved him. Michael was groggy, his head hurt a little (from the medication they gave him), and his stomach was still hurting him. He could not reach it to hold because his wrists were still secured. Inside his room he was placed on another stretcher, still restrained to the backboard. The rails were up on the stretcher, securing him in place. He looked around and saw a metal wall to his right and bright blue paint all over the walls. A television was stuck in a plastic box up on the wall and it seemed like the volume was turned all the way up.

Michael screamed in pain as his stomach began to hurt him. He heard the people all around him talking more and more about him. Before Michael even had a chance to take in the rest of his surroundings, a man wrapped a tight rubber band around his arm. He had experienced this the last time he was in the emergency department. Just like before, the people never explained what they were doing. The band was very tight around his arm. Michael tried to move his arm upward to grab at the rubber band, but his arm was still secured. The people began to yell and shout at him with his movement. The man who had tied the tight band on his arm began to wipe the inside of his elbow with a cold and wet wipe. The other people standing around him held him down at different points of his body. Michael's shoulders were held to the bed, his arm was held by the man that was wiping his arm, and his legs held by an even larger man at the bottom of the bed.

Michael felt a sharp pinch in the crease of his elbow as he looked down. He was being poked with a needle. He remembered this from the last time he was here as well. His blood began to trickle down the tubing into three containers with different colored tops. He didn't like this. This reminded him of other times he had been here when they hadn't explained what they were doing, and he stayed in the same room for days. This time his stomach really hurt, and nobody had tried to ask him what was going on that day or why he was upset.

The man collected the blood in the tubes and put them in a plastic bag. The other people holding Michael to the bed had left and the nurse wheeled a computer in the room and started typing loudly. The clicks and clacks of the keyboard annoyed Michael. They were loud.

“Okay Michael, the doctor will be in soon,” the nurse shouted from the doorway. She left with her computer on wheels as another person pulled up on a computer and sat directly in the doorway. There was always someone sitting there watching him. Nobody had tried to ask him how he felt, what was hurting him, or how he even got here in the first place. This was just like every other time. Although Michael spoke very little, he had been trying to point to his stomach. But still his arms were tied to the bed. There he would sit, waiting for the doctor. The lights in the room were on and bright, and the television was still on. Michael felt helpless and nobody seemed to care.

Chapter 3: The Differential Diagnosis: Altering the Paradigm, An Invitation

Current practice in the care of the autistic person is grounded in paternalism. Hens noted that, "[autistic persons] have limited control over impulses, or their behavior is steered by strong preoccupations, which may greatly influence the choices they make" and as a result, "their caregivers, friends, and the institutions that are designed to protect their interests, to be paternalistic" (Hens 2019). Hens offers that these paternalistic tendencies impact other facets of the individual's life (2019). The strong paternalistic nature exhibited by caregivers of autistic individuals extends to their treatment within medical institutions. Narrow considerations of the four principles of biomedical ethics, recognized by Beauchamp & Childress, do not suffice in the care of the autistic person (2019). Principles alone do not suffice in guiding the considerations that must be made of the autistic experience when ethically examining scenarios, especially within the medical environment. Considerations of non-maleficence, beneficence, respect for autonomy, and justice are overlooked at times to make room for paternalistic care plans based upon what treating teams believe is warranted for their patient. In the pediatric and adolescent populations, considerations such as that of patient assent is often overlooked, especially in patients with varying communicative abilities.

Often these care plans are beneficence-based (in the eyes of the provider), taking into account tradeoffs between autonomy and beneficence, creating a care plan that provides the maximum amount of benefit to the patient. However, it should be recognized that a principal-based approach in the development of a care plan, based on the expertise and practice of the provider, may not take into account preferences of the patient and their caregiver. This is important considering the lived experience of the autistic patient may be a guiding factor in how principals are applied to specific situations. This is a critical limitation of principalism in that is fails to take into account other factors that may be influencing a situation (Nimmagadda 2017). For example, a provider may think that a patient may benefit from a calming sensory device. However, a caregiver may know that the patient does not benefit from them. A principalist approach would assume beneficence (solely because it is deemed beneficial by the provider) without consideration of the preferences or lived experience of the patient.

While these principles are not forgone altogether, the harmonization and balance of principalism and an ethics of care will prove beneficial in the ethical considerations of the autistic patient to restore empathy and patient-centered care (Martinsen 2011).

In this chapter, we will explore the concept of care, a brief history of the ethics of care, and the emergence of the growing field of autism ethics, ending with an invitation to consider a new paradigm through which we view care for the autistic patient. A paradigm rooted in the principles that guide biomedical ethics, but enhanced through a lens of care.

What is Care?

The concept of care can be derived from the term *cura/curare* within the Latin literature of Ancient Rome. Two conflicting definitions of the term can be found; one describing worries and anxieties as one "burdened with cares" and another describing the act of providing for the welfare of another with "attentive conscientiousness and devotion" (Reich 1995). For the purposes of the considerations of this work and the theory of care ethics, we will focus on the second derived meaning.

In healthcare, the concept of care in practice translates to providing attention and interventions to the sick or suffering (Reich 1995). The notion of care has been tied to the profession of nursing, while curing is most often tied to physicians and doctoring (Martinsen

2011). Jecker and Self argue that this association is misleading for many reasons. Centrally, both doctors and nurses are fundamentally involved in caring for patients. They also argue that meanings of the term “curing” are derived from caring – as cure comes from the same Latin term *cura/curare* (Jecker & Self 1991). It should be recognized that the common goal of relieving suffering is shared in both fields of medicine and nursing. As a result, the goal of “relieving suffering” should ground both the role of physician and nurse in their respective roles.

A review of the literature reveals that the concept of care has been accepted more within nursing ethics (McCabe 2008). However, care represents a vital component of ethics in medicine (Reich 1995). In a review of Cassell’s 1982 work on human suffering, Warren Reich explains that, “caring is inextricably linked to the physician’s obligation to relieve suffering” (Reich 1995). Interestingly, Cassell explains the existence of a “modern paradox” in which the duty of physicians to relieve suffering goes back to antiquity, however, suffering is still experienced throughout the disease process and during treatment (1982). Cassell explains this in the setting of the mind-body dichotomy that has dominated perspectives in medicine. He states that the body is often paired with medicine, while the mind is left to be associated with abstract understandings of the person and personhood, instead of viewing the patient as a whole (Cassell 1982). As a result, the mind-body dichotomy has led to “a failure of knowledge and understanding” where “suffering remains subjective or exclusively related to bodily pain” (Cassell 1982). The failure to understand suffering beyond biomedical interpretations of pain, rather than through perspectives of a lived experience, prevent care teams from fully understanding the extent of suffering. Cassell’s work illuminates the importance of understanding patients as a whole rather than through “reductionist scientific methods” (1982).

This "modern paradox" exists decades after Cassell's work, as it permeates all specialties of medical practice through most disease processes and treatment plans. It is particularly evident in the care of the autistic patient as they experience interventions from laboratory draws to overstimulating environments and poorly understood treatments. Care should be a central tenet in the practice of all healthcare providers (nurse and physicians, alike) in an effort to relieve or prevent suffering. Perspectives on suffering provide a foundation to further explore the theory of care ethics that will situate arguments for a new paradigm of autism care ethics.

Toward an Ethics of Care

Derived from feminist philosophical and psychological thought, the ethics of care or care ethics, has struggled to gain traction in medical ethics for decades. (McCabe 2008). The work of Carol Gilligan (*In a Different Voice* 1982) and Nel Noddings (*Caring* 1984) pioneered the care ethics movement. Their theories have led to subsequent exploration of an ethics of care and its application to a range of fields from education to medicine.

Gilligan's work focused on the real-life moral decision-making of women. Her theory stemmed from the claim that women did not appeal to generalized principles or make assertions of what is right or wrong, but focused on "the limitations of any particular resolution and describe the conflicts that remain" (Gilligan 1982). She explored the considerations of "Amy" who presented with a perspective that was grounded in "a narrative of relationships that extend over time" and in "a world that coheres through human connection rather than through systems of rules" (Gilligan 1982). Gilligan's focus on human connection offered insight into the importance of human relationships and how they inform decisions and perspectives. Stephanie Collins offers that this finding led to the establishment of an ethics of care that was "contextually embedded" and "relationship-oriented," aspects that have guided the theory ever since (2015).

Ethics of care is "contextually embedded," as ethical considerations of care and caring acts should be dependent on the context in which the individual's circumstance is situated. It is "relationship-oriented" as relationships guide both the context of interactions and the dynamics between individuals that may guide further ethical determinations. These principles are foundational to understanding how care can guide ethical decision-making within specific situations and lived experiences of an individual.

Care ethicists theorize that ethical responsibilities are derived from relationships between individuals and are not principle-based. Decision-making should be "sympathy-based rather than duty or principle based" and personal relationships have "a value that is often overlooked by other moral theories[13]" (Collins 2015). However, this is not to say that care ethics cannot co-exist or even be complimented by many of the leading bioethical principles pioneered by Beauchamp and Childress, now termed principalism (Collins 2015). A criticism of principalism is that it assumes a common morality and moral norms (Walker 2009). In the autism community, principles such as autonomy may have different meanings than autonomy for a neurotypical peer. As a result, an added dimension is needed to understand how a principal may manifest itself in a specific situation or amongst a common identity.

Nel Noddings developed the ethics of care into a complete ethical system that could function independently (McCabe 2008). She offered that the focus of an "ethics of care" was "the caring relationship between specific individuals, at specific times, in specific contexts" (Noddings 1984). Building on Gilligan's principles of context-dependence and relationship-orientation, Noddings offered components of the caring relationship through focus on the care-

---

[13] Of note, care ethicists do not claim that other moral theories "get nothing right" but rather that the aspects of interpersonal relationships go overlooked. (Collins 2015, Engster 2007, Held 2004, Tronto 1993)

giver, sensitivity to context, partialism, and proximity (1984). All of which are aspects of Noddings' theory that further developed care ethics into a stand-alone ethical theory.

In the focus on the care-giver which Noddings called the "one-caring," she described a level of "engrossment" that the "one-caring" develops about the "feelings, wants, and plans of the cared-for" (Noddings 1984). "Engrossment" has been described as "a deep form of empathy" (McCabe 2008). Noddings describes that "engrossment" encompasses a form of "nonselective attention" in an attempt to avoid "equating intellectual and interpersonal attention" (Noddings 1992). She provides an excellent analogy through mathematicians and their attentiveness to mathematics stating, [a mathematician] can be "attentive to mathematics and obtusely incapable of attention to people" (Noddings 1992). This parallels how a physician may be attentive to the science of medicine, but unaware of additional considerations (emotional, cultural, etc.) of their patient. Care ethics offers an important application to medicine, that ethical considerations of the patient and their care may extend beyond the biomedical; a consideration critical to the integration of care ethics into practice and its relatedness to concepts of empathy.

Noddings warns against a "faulty sentimental interpretation" of "engrossment" which can be found in criticisms of "engrossment" in its application to medicine and nursing (Nelson 1992). When paired with the "contextually-embedded" and "relationship-oriented" nature of care ethics, "engrossment" in the physician-patient and nurse-patient relationship should manifest itself within the confines of what is ethically appropriate in these relationships and patient-care contexts (Gilligan 1982, Noddings 1984, Collins 2015). The relationship of the "one-caring" and the "cared-for" is essential in the relationship orientation that guides care ethicists. It is also crucial in its applicability to the act of caring as exhibited by physicians and nurses when applied to medicine, as the medical professional takes on the role of the "one-caring" while the patient takes the role of the "cared-for." Thus, the actions that the medical professional takes as the "one-caring" are embedded in the context of their role and relationship to their patients.

"Engrossment" as first proposed by Noddings (1984) has created controversy in its application to medicine and nursing ethics (Nelson 1992). Nelson outlines in her critique that the concept of caring put forth by Noddings, rejects the principle of justice. She characterizes caring as "inherently partial" with only consideration given to those "within the caregiver's scope" while justice is "inherently impartial and universal" (Nelson 1992). While Nelson explains the differences between caring and justice, she fails to reflect that the two may be able to co-exist as complementing principles for the caring actor. Justice and caring should be permitted to complement one another, especially considering limitations of principalism in its limited dimensionality.

Nodding's second characteristic of an ethics of care explores context, furthering Gilligan's context-dependent principle. In an "Ethics of Care" the "one-caring" is invested in the "fine details" of each case as well as the expressed and unexpressed, or even inferred wants and needs of the "cared-for" (Noddings 1984). It is instead these considerations rather than principles that guide moral decision-making. As we relate this to healthcare, particularly in the care of autistic patients through this work, physicians and nurses are engaged in the many "fine details" of the patient's care plan that transcends not only the biomedical perspective, but the sociocultural and environmental considerations as well. It is the "fine details" that may inform aspects of decision-making harmoniously alongside an ethical principle. This is because the circumstance of a situation may be far more complex than the simple guidance of an ethical principle, especially when principles may conflict or manifest outside of a common morality (Nimmogadda 2017, Walker 2009).

Providers are actively weighing aspects of the patient's wants and needs, as they are expressed or inferred by the healthcare team. This is often dependent on the capability of the patient to express their desires. This particular limitation may require particular attention or prowess in caring for the autistic patient who may have a different communicative style. This may leave room for extensive interpretation and potential for misinterpretation and misunderstandings. Additional ethical considerations regarding these inferences, could potentially be benefited from a perspective informed by both care ethics (considering the desires of the patient) and autism ethics (through a lens informed by the autism community). Particularly, as to what extent individual capabilities can be inferred and by whom they can be inferred, especially as it pertains to medical care.

Partiality and proximity are two other characteristics of Nodding's theory that differ from principalism and other traditional ethical theories. In its partialistic nature, Noddings suggested that individuals are obligated to direct care for different people in different manners based upon their relationship (1984). She portrayed this through the depiction of concentric circles and chains that describe inter-relatedness of relationships and our obligation to care depending upon our degree of "closeness." Noddings acknowledged that the length of association, the intensity of relationship, and the degree of formality of the relationship are all factors that can contribute to "degree in which one cares" (1984). Proximity is a crucial factor of these relationships as well and it contributes heavily to considerations of partialism (McCabe 2008). Noddings called those who are inclined to care for another due to their proximity to one another, "proximate others" (1984). This is evident in relationships formed between co-workers, student-teacher relationships, and even the patient-provider relationship, all of which are relationships dependent solely on proximity. The patient-provider relationship is of particular interest in the relationship-oriented nature of care ethics. The application of this specific relationship to care ethics could comprise of its own project, due to the many perspectives on what constitutes this relationship, what should limit this relationship, and the form in which this relationship should exist.

The components discussed previously often result in criticisms due to the "emotional and partialistic dimensions of caring" (McCabe 2008). As a result, when utilized in medicine, concerns arise of emotional attachment and threats to the equal treatment of all patients (Curzer 1993). To counter these critiques, McCabe utilized the work of Slote (2001) and Manning (1992) who offered insight on additional considerations of the ethics of care that address these main concerns (2008). These considerations are necessary for the applicability of the ethics of care within this work and for its use as a stand-alone theory in medical ethics.

In considering these arguments, McCabe focused on Rita Manning's work, *Speaking from the Heart (1992),* in which she explored the needs of the one being cared-for. She delineated between what she termed "subsistence needs," those that one needs to survive, and "psychological needs," those that are necessary for human flourishing (Manning 1992). The identification of "subsistence needs" is crucial in understanding how the one-caring does not have an obligation to meet every single need that an individual may have. It is also an important aspect of understanding how a "caring agent like a physician, will direct their concern to an individual through action" (McCabe 2008). From the agent-action perspective, a physician may direct concern for their patients in the care that they deliver, whether that be through specific diagnostics practices, conversations tailored to different aspects of the patient's well-being, or even a the "engrossment" that guides the physician-patient relationship (Noddings 1992). This added nuance, aids in preventing the potential emotional attachment that critics fear is inherent in care ethics. Utilizing this perspective, the physician only has an obligation within their formal role to meet “subsistence needs.” For example, a physician may have the ethical obligation to provide blood pressure medication for a patient with severe chronic hypertension to meet the “subsistence needs” of the patient. However, this obligation does not extend into meeting “psychological needs” of the patient that may promote human flourishing. For instance, taking the same patient to the grocery store weekly to guide selection of low-sodium foods, to positively impact long-term health outcomes, related to their hypertension. This example meets the “psychological needs” of the patient and would go beyond meeting the patient’s “subsistence needs.” Thus, meeting the physician’s ethical responsibility in their role.

Manning further addressed concerns related to the partialistic nature of an ethics of caring through a feature she called, “relationship awareness” where she recognized the varying degrees of relationships that existed within the human condition (Kuhse and Singer 1998). Particularly, she examined this within the physician-patient relationship as, “the acknowledgement of and commitment to the responsibilities associated with the role(s).” The specific role that one holds will often dictate the needs of others that one will serve (McCabe 2008). Within medicine, “subsistence needs” are the focus, particularly in emergency department setting, with the physician serving in the role of the “caring agent.”

Michael Slote’s, *Morals from Motives (2001),* argued that “[an] ethically caring motive is the basis of all moral judgements.” He described the consideration of the principle of “balanced care.” In “balanced care” one weighs objects of care in three distinct categories; those who are near and dear to us, distant strangers who are unknown to us, and the one-caring (Slote 2001). These three categories allow the “one caring” to weigh their considerations of self-interests and well-being against the needs of different classes or groups (rather than individuals), to preserve self-interests. As a result, in medicine, this allows for the physician to protect their own interests, for example, against burn-out, with the competing needs of their job duties (patient care, administrative work, research, etc.).

McCabe's integration of both Slote's "balanced caring" and Manning's "subsistence needs" and "relationship awareness" are crucial to the applicability of the ethics of care as described by both Gilligan and Noddings to the practice of medicine (2008, 2001, 1991, 1982, 1984). These considerations are essential to addressing critiques of care ethics to allow for the development of the proposed autism care ethics paradigm outlined in this chapter.

Autism Ethics: A Blossoming Area of Ethical Consideration

Autism has created much disagreement amongst scholars due to its heterogeneity and "polysemous" nature (Hens, 2018). Those with autism experience and interact with the world differently than their neurotypical peers. Of particular importance is the degree at which these experience and interactions differ ranges between autistic individuals. As a result, a diagnosis of autism can mean many different things depending on profession and even personal experience. For instance, the DSM-5 (American Psychiatric Association 2013) as previously outlined in Chapter 1, explores ASD through observations of different behaviors and the assessment of relative dysfunction. However, Hens noted that clinicians may not only point to "challenging behaviors" when discussing autism but will also refer to "information processing or sensorial processing" that is rooted in deeper neurocognitive theories of autism (2019). As a result, there are many different perspectives from which one can approach an autism diagnosis that leads to disagreement on what actually encompasses autism.

There have been many shifts of the meaning of autism throughout the years. The shifts in the diagnostic category of autism have been given multiple explanations due to heterogeneity amongst the behavioral, cognitive, and genetic underpinnings of autism (Hens 2019). However, the label of an autism diagnosis has led to the development of an identity of the autistic individual, as Hens stated, "being autistic is seen by many people as an integral part of their identity" (2019). With this identity comes an evolving set of questions related to the autistic experience, in which autism ethics have taken root.

The experience of the individual with autism presents unique ethical questions that cannot be answered solely by those without autism. An understanding of autism through lived experience is needed to adequately approach these questions. Hens argued that the emerging field of the "ethics of autism" cannot be practiced "from the armchair" and requires "interaction with, and input from, autistic people" (2019). Some of the ethical questions that Hens asks within her proposal for an "ethics of autism" are:

- *"Is autism an identity or a personality trait rather than a disease or disorder that can be cured or prevented?"*
- *"Can a non-autistic person really know what autism is?"*
- *"Does the atypical neurology of autistic people affect their epistemic authority?"*
- *"Does the specific nature of autism force us to rethink default accounts of justice, autonomy, and paternalism?"*
- *"How could we organize our societal practices in such a way that autistic people can talk about themselves, their choices, and their difficulties?"*
- *"What do we owe autistic children and adults so that we can understand them properly?"*

Hens' ethical questions outlined the ambiguity that persists in our current view of autism, while challenging how individuals with autism are currently treated within our society. It can be argued that an approach grounded in care ethics would provide a perfect lens to view the specific needs, wants, and desires of the autistic person (Noddings 1984). Thus, an autism care ethics is necessitated to effectively meet the needs to the autistic person in society, particularly in this work, as they interact with medical professionals.

A New Paradigm: Autism Care Ethics

In combining the notion of care, the theory of care ethics, and emerging autism ethics, an autism care ethics would be best suited to meet the needs of the autistic individual. The "heterogeneity" and "polysemous nature" of autism provide challenges to current ethical approaches that typically guide considerations for vulnerable populations and identity groups. Principles such as justice and autonomy are frequently cited as necessary for these populations, however these views may be blinded by normative perceptions of these principles by neuronormative populations (Hens 2019). The context-dependence of care ethics allows for the "fine details" of the autistic experience to be applied to ethical considerations alongside the foundational principles of justice and autonomy (Noddings 1984). Relationship-oriented aspects of care ethics allow for important considerations for caregivers, "proximate others," and the autistic "self." These perspectives would otherwise not be taken into account in a strictly principalist ethical approach. It is for these reasons that an autism care ethics is proposed. An ethical paradigm blending care ethics and autism ethics works to best inform providers on how to deliver ethically informed care to autistic patients.

Autism Care Ethics (ACE) will center around three guiding concepts, the first being an acknowledgement of the heterogeneity of autism and the recognition that the autistic experience cannot be fully understood by those without autism. The promotion of the perspectives of autistic individuals, particularly regarding approaches to their care in the medical setting, is important in this domain. As previously mentioned, principalism is limited by a normative perspective of each ethical principle. ACE will explore what each principle may look like to an individual with autism by way of their own lived experience. This is critical to the development of an approach that is person-centered as well as context-dependent (which we will discuss in the next domain). A person-centered approach in this domain of heterogeneity allows for the autistic community to share their perspective and experience while grounding ethical considerations in their lived experience. The first domain acknowledges that many individuals in the autism community may experience autism differently. It also highlights the necessity to amplify the voices and perspectives of autistic individuals within the theory.

The second concept of ACE is that “carers” or “those caring” rely heavily on context dependence and relationship orientation to direct caring tasks. This effectively highlights the importance of relationships and the application of circumstance to each specific ethical consideration. This domain is grounded in the concept that ethical considerations may be different for the autism community than for neurotypical peers, especially in medical ethics. For example, a patient with autism may not have an avenue to express their wishes for their care in the current ethical approach to patients with autism. Thus, context dependence and relationship orientation are critical in informing important circumstances that may sway ethical decision-making. For considerations of ACE, context dependence can be defined as the circumstances in which care or an interaction of caring behaviors takes place. Relationship orientation in the ACE framework, situates all of these interactions within a relationship between a “carer” and the “cared for.” Relationship orientation, specifically in the provider-patient relationship, allows for

ACE to become properly integrated in a manner that respects some limitation of this important relationship.

A final concept explores the idea of attunement (or what one can imagine about the lived experience) and empathy are needed to attempt to understand the autistic experience and guide caring acts. This integrates many of Jodi Halpern's ideas concerning empathy (which will be explored at this end of this work) back into medical approaches to caring for the patient with autism. A provider utilizing ACE will be attuned with the experiences and perspectives of the autistic patient. An attuned and empathetic provider would be able to meet the needs of the patient efficiently, allowing the patient to inform and guide aspects of care. This is critical, especially when considering the limitations of understanding that neurotypical providers may have of their autistic patients.

There are many aspects of the autistic experience in which autism care ethics can be applied, for the purposes of this work we will utilize these three guiding concepts to apply ACE to the experiences of the patient with autism in the acute care setting, particularly in the emergency department. Although the paradigm will be presented for use in the acute care setting of the emergency department, an invitation to extend autism care ethics throughout medicine may prove beneficial to the autism community. This proposed combinative theory hopes to address, more holistically, the ethical concerns faced by the autism community as they navigate medicine and society.

Autism Care Ethics: An Approach to Care for Michael

An emergency department visit that was situated in autism care ethics would have drastically transformed Michael's experience. First, the paramedics and police officers responding to Michael may not have been so quick to restrain him both physically and chemically. These team members would have worked to understand Michael's communicative baseline and would have worked with his mother to gather a history. The team could have also discussed previous interactions with EMS and police to prevent any triggering or potentially escalating behaviors in the pre-hospital setting. Developing an understanding from a caring and patient-centered perspective may provide potential ways to prevent further escalation or may even work to assist in de-escalation of an agitated autistic patient. For example, the lights and sirens of the ambulance be turned off as they are potentially over-stimulating. Changing aspects of care to meet the needs of the patient is a crucial aspect of adapting current practice to one rooted in autism care ethics.

A nurse's approach to autism care ethics for Michael would have worked with EMS and the patient's caregiver to collect more information about Michael. The nurse would have considered a quick look through the EMR for a care plan and any previous stays that might contain any pertinent information. Even in the past paced nature of triage, this could have completely turned Michael's visit around. The nurse could have also talked to Michael and not just assumed his limited ability to communicate or understand her. Throughout Michael's narrative he feels unheeded and misunderstood. There were no actions taken to explain any procedures to him and NIPs were ordered, performed, blood was drawn, when Michael had not yet been examined by a physician. Throughout the narrative, Michael expresses thoughts of re-traumatization, where he remembers aspects of his previous medical encounters. Autism care ethics would provide trauma-informed care that prevents potential re-traumatization. For example, while invasive procedures such as venipuncture many not be able to be provided, a nurse guided by ACE will ensure that appropriate resources are in place (a child life specialist, distraction items, etc.) to prevent further traumatization from the procedure.

Most importantly, Michael was being treated as a behavioral health patient due to his aggression on scene. However, this aggression was masking his true complaint which was his stomach. Autism care ethics would situate caregivers in the conversation so that they can consider other manifestations of this behavior through attention to the "fine details" while building rapport and a relationship with Michael and his caregiver.

While the narrative did not yet progress to interactions with the physician, a timely presence of the physician after chart review could be helpful. The narrative was focused to the first hour of Michael's presentation, even before a physician examined Michael to stress how the paradigm of autism care ethics can transform care from the pre-hospital setting, to nursing care, to physician medical decision making.

It is also pertinent to mention that this narrative is crafted from both research and generalizations. Aspects of the autistic experience were derived from research related to triggers and associated diagnostic criteria. It is not the intention of this work to speak for the autistic individual or the autistic experience, but merely to present a narrative through which autism care ethics can be better understood and appreciated. Generalizations of attitudes and emergency department processes are informed by experiences and interactions with autistic patients in the clinical setting. This narrative is not meant to reflect any single patient or healthcare worker that may have participated in a similar care situation.

Chapter 4: Medical Decision Making: Ethical Implications of Current Practice

This chapter will explore the integration of autism care ethics in conjunction with medical ethics principles in many of the difficult considerations that providers face when caring for the autistic patient in the emergency department. Aspects of autism and emergency department care previously discussed in Chapter 1 and Chapter 2 will be examined through the ethical framework discussed in Chapter 3. This chapter will apply autism care ethics to the relationship between behavioral health and autism, chemical and physical restraint use, and medically unnecessary procedures. The three areas chosen to further explore and situate within autism care ethics represent three areas of care for the ASD patient that present potentially alarming ethical issues. They offer the opportunity to highlight the need for further ethical considerations situated in autism care ethics. These recommendations are merely a starting point for the ethical considerations of care for the autistic patient through the proposed lens of autism care ethics.

Behavioral Health & Autism

The inherent categorization of patients presenting to the emergency department with a history of ASD as solely a behavioral complaint fails to acknowledge the barriers that patients with ASD may have in the ability to communicate and express their wants and needs. This failure of acknowledgement is rooted in a tendency (especially in fast-paced and high-volume emergency department settings) to categorize a "one size fits all" descriptor to a patient for ease of triage, nurse-initiated protocols, and assessments. As Iannuzzi has alluded to, providers should take caution when examining autistic patients presenting with self-injurious or aggressive behaviors as being solely secondary to a psychiatric or behavioral condition as "medical conditions may be the root cause of aberrant behaviors" (2015).

In approaching this situation from the angle of autism care ethics, healthcare providers should pay special attention to specific wants or needs that can be expressed by the patient in addition to any communicative efforts. For instance, when Michael grabbed his stomach or was wincing in pain, these non-verbal cues were hinting at an underlying problem that went unnoticed. As in Michael's narrative, these actions may hint at the presence of underlying medical conditions causing behavioral escalation. Effort should be made to promote communication via the patient's preferred communication method. These wants and needs can be effectively obtained from history-taking with the patient (considering the patient's communicative ability and communicative preferences) as well as their caregiver. Efforts should be made to review the medical record for previous encounters and applicable coping plans, if provided by the institution or even the parent or caregiver. The combination of this information provides a patient-centered perspective in which providers can examine patient behaviors, etc.

A healthcare provider utilizing autism care ethics as it pertains to this concern would be particularly focused on the context-dependent nature of caring (Gilligan, 1982) that care ethics promotes within the provider-patient relationship. The circumstances surrounding the presentation of the autistic child to the emergency department, paired with the details collected from history-taking and physical exam, will guide the provider to make patient-centered treatment decisions rooted in care.

These considerations have strong ties to the principle of justice as it applies to the mischaracterization of patients with autism, based distinctly on their autism diagnosis. Justice in this sense can be simply derived from the basic description provided by Beauchamp and Childress in their summary of perspectives of justice as, "giving to each his due" (2019). In this case, the "due" being the equal consideration of the medical team's ability to diagnose and treat without interference from biases and stigma related to an autism diagnosis. It should be an ethical concern to providers that medical history can bias objective patient assessments, especially with psychiatric and behavioral health concerns where signs and symptoms are easily attributed to a previous diagnosis, in lieu of an exam. A patient-centered mindset would prioritize aspects of patient presentation (physical exam, medical history, demeanor) that would other have been ignored by biases attributed to a past psychiatric diagnosis.

Aggression and violent behaviors have been known to be associated with ASD and other co-morbid psychiatric disorders (Hossain, 2020). However, there is a hesitancy amongst providers to explore manifestations of these behaviors outside of autism. As a result, the principle of justice cannot be enough to ethically guide the behaviors of the medical team as it lacks the context-dependence that autism care ethics would add. An assessment grounded in justice, but enhanced by autism care ethics, would ensure that all patients with autism are given adequate examination considering aspects of their lived experience as they present to the emergency department. While an equitable exam to any other patient in the emergency department is a manifestation of the ethical principle of justice, the context dependence of patient behaviors and expressions are a manifestation of the care ethics. Together, in the paradigm of autism care ethics, patient needs can be addressed accordingly. Utilizing details available from the patient, their caregiver, and the provider's own intuition, the patient's "subsistence needs" can be met leading to effective and ethically appropriate care (Manning, 1992).

Restraint Use (Chemical & Physical)

Both chemical and physical restraint are used in managing behavioral health patients, particularly restraints are used for those presenting with aggression. As estimated by Dorfman, 6-8% of the total pediatric behavioral health population require some form of restraint (2004 & 2006). There is reason to believe that the use of restraint is particularly higher as the prevalence of restraint has not been examined in further detail since these studies. Given the rise in behavioral and mental health complaints during the COVID-19 pandemic, particularly among children, ages 5-11, a 24% increase, and adolescents, ages 12-17, a 31% increase, an expected rise in restraint should be expected but has not been further examined (Radhakrishnan 2022, Leeb 2020). As a result, the ethical considerations of care of the autistic patient and the use of physical and chemical restraint should be considered in the context of autism care ethics.

The ethical principles to be considered when examining the use of chemical and physical restraints are non-maleficence and respect for autonomy. Non-maleficence is pertinent as it is the healthcare team's duty to prevent harm to the patient (Beauchamp & Childress 2019). Chemical restraints present a specific risk for the patient with autism in the form of adverse drug events (Gerson 2019). Potential harm to the patient from these events could negatively impact patient outcomes and even patient beliefs and understandings regarding their treatment. The possibility of re-traumatization from restraint for autistic patients is also a significant risk. It is one that is often overlooked and could be reduced through the integration of autism care ethics and a trauma-informed approach (Forkey 2021; Heppell 2018). As chemical restraint is typically administered intramuscularly (IM), the rate of previous trauma from blood draws, intravenous line insertion, or IM medication administration may be possible sources of pre-existing adverse experiences and trauma for the patient with autism. It is important that healthcare teams consult the patient (if appropriate), their parent or caregiver, and the medical record to examine potential triggers or sources of traumatization.

Patient autonomy refers to self-rule that is free from controlling interference by others and the limitations that prevent meaningful choice (Beauchamp & Childress 2019). Actions of restraint may hinder the autonomy of the autistic individual (Cheung 2005). It is important that providers are aware that the perceived cognitive ability of the autistic patient should not bias medical decision making. Particularly as it has recognized that the autistic experience is not fully understood by those without autism and as a result, principles such as autonomy may be reflected differently amongst neurodiverse populations (Hens 2019). Efforts should be made to protect the autonomy of patients presenting with autism just as healthcare providers would any other neuro-normative patient. Adapting to the communication style of the patient to explain actions, exploring any available history and/or coping plans, and the integration of de-escalation techniques are all tactics that providers can employ to protect patient autonomy.

An autism care ethics-based approach to chemical and physical restraint would involve leveraging aspects of the provider’s relationship with the patient and the patient’s parent or caregiver to prevent chemical or physical restraint, considering the harm that restraint could have on these relationships and the overall experience of the patient. It should be noted that rapport and relationship-building can be promoted between healthcare providers and patients with autism regardless of their communication barriers, etc. (Mazurek 2021). Utilizing techniques such as therapeutic verbal communcation to de-escalate aggressive behaviors may prove helpful and could be informed via communication or through the use of a coping plan[14] (McGonigle 2014, Gerson 2018).

Additionally, it is important to acknowledge that chemical and/or physical restraint may be necessary in treatment of aggression and other behaviors for the safety of the patient and the healthcare staff (Heyneman 2003). Efforts should be made by the healthcare team to limit the use of restraint as much as possible to adhere to using the least restrictive means and to deliver care focused within autism care ethics. The least restrictive means is an ethical commitment that has stemmed from the least restrictive alternative standard (LRAS) in mental health law as a result of statutory and case law for use in coerced treatment (Olsen 1998). In clinical ethics, least restrictive means is utilized to adhere to the principle of justice while ensuring respect for patient autonomy. This is done in an effort to decrease potential harm to patients. It is pertinent that the least restrictive means be considered when examining interventions that would significantly impact patient autonomy, such as physical and chemical restraint.

Throughout the care timeline, providers should be particularly mindful of efforts to protect the autonomy of the autistic patient, while working to develop relationships with the patient and their caregiver. This may help to inform the provider of what autonomy would look like to the patient (i.e., does the patient normally make choices for their own care, what do these choices usually consist of, are there ways in which providers can better communicate these choices to the individual). This perspective is essential in balancing many of the considerations that the physician must make when utilizing an autism care ethics approach when restraint may be indicated.

Unnecessary Invasive Procedures

Medically unnecessary venipuncture for medical clearance could be prevented through a plan of care enhanced by a lens of autism care ethics. Venipuncture necessitates exposure to needles, pain and

---

[14] It should be recognized that a coping plan is particularly useful in the acute care/acute behavioral de-escalation setting, only if filled out during a previous admission and stored in the medical record. Previous work has been done to integrate the coping plan into check-in procedures during ED presentation (Wittling, 2018).

discomfort, possible chemical or physical restraint (to obtain specimens), and other potentially noxious stimuli (tight tourniquets or wet/cold anti-septic wipes) that may further agitate or serve as an initial trigger for patients with autism. Therefore, efforts should be made to prevent medically unnecessary venipuncture acknowledging non-maleficence while situating care for the patient in autism care ethics (Hurley Forthcoming).

In examining medically unnecessary venipuncture through the lens of autism care ethics, these unnecessary procedures would be avoided due to a provider's reliance on the "fine details" that would come from a detailed history and physical (Noddings 1984). As a result, venipuncture may be indicated after an examination of the patient. However, in the case that it is not, the autistic patient has been spared from an adverse experience. It is essential that providers dedicate their care to examining the "fine details" when caring for the autistic patient.

A Lack of Empathy or Detached Concern?

It is difficult to examine the circumstances of this project, particularly as it is applied to a vulnerable patient population such as autistic children, without questioning where the practice of medicine potentially bypassed elements of empathy and the art of caring for the whole person. Aspects of care such as unnecessary procedures and prolonged physical or chemical restraint are in direct conflict with many of the guiding principles of biomedical ethics (Beauchamp & Childress 2019). The work of Jodi Halpern, examined clinical empathy and the lack thereof in medical practice today and highlighted why many of these actions have gone unnoticed and unchanged for so long.

Halpern wrote, "doctors strive for detachment to reliably care for all patients regardless of their personal feelings" (2003). She explored the concept of "detachment", reflecting on decades of perspectives of expectations of the medical education community that physicians "feel nothing in response to something" (Halpern 2003). Utilizing William Osler's view of detachment, where it is suggested that physicians can "see into" the patient's "inner life", thus standing apart from the patient in observation (1963). This is contrasted with empathy's role in "feeling into" an experience (Halpern 2003). As a result, there is a direct conflict with the genuine empathy that patients and their caregivers expect from their doctors and that physicians want to provide (Bertakis 1991). In the instance of unnecessary invasive procedures, is detachment the reason that these practices have lingered?

Detachment may be why these issues linger and why the biomedical ethics principles that have guided medical care need to be situated in an ethics of care. In the instance of unnecessary specimen collection for medical screening, over a decade has passed since Dr. Thomas Chun's 2014 call to end medical screening for behavioral mental health patients to the American Academy of Pediatrics' Pediatric Emergency Working Group's recommendation to end the practice in their 2024 *Choosing Wisely Campaign* (Chun 2014, Mullen 2024). A more empathetic, or perhaps "less detached" provider may be able to effectively meet the specific needs of their patient. Further derivations of this to meet the specific needs of patient populations, as in the case of autism care ethics, provide a lens through which effective patient-centered and patient-specific care can be delivered thorough an ethically permissible means.

Detachment is undeniably why care ethics has struggled to gain traction in medical practice (McCabe 2008). Halpern offered many reasons as to why empathy must be reintegrated into the practice of medicine. She relied heavily on the concept of emotional attunement, which "operates by shaping what one imagines about another person's experience" (Halpern 2003). This can be effectively translated to autism care ethics. A provider should be focused on meeting the specific needs of the patient. As a result, providers should utilize empathy to consider the lived experience of the autistic patient. In an effort to meet the unique needs and perceptions of the patient with autism, the provider must utilize Halpern's clinical empathy to deliver patient-centered care. Currently, detached concern permits a "one-size fits all" mindset which has led to many of the ethical concerns that we have explored in this work.

Jodi Halpern defined empathy as an "experiential way of grasping another's emotional state" that is "perceptual" and "operates alongside logical inquiry" (2003). Physicians should be able to pair their objective reasoning and empathetic intuition in order to effectively care for a patient. She offered that, “empathy should enhance medical diagnosis rather than detract from it” (Halpern 2003). This is similar to many of the parallels that are discussed regarding enhanced patient care for the autism population within this work. For example, enhancement related to the pairing of biomedical perspectives with sociocultural perspectives of care to effectively treat the whole person. Halpern offers that, “empathy enhances the patient-physician communication and trust, and therefore treatment effectiveness” and that “physicians who allow their patients to move them enrich their own experience of doctoring” (2003). It is essential that physicians develop rapport and trust with autistic patients and their caregivers, even in the fast-paced emergency department setting. Rapport and trust will allow for effective communication and will provide the medical team with an understanding of the “fine details” of the patient’s presentation (Noddings 1984).

Reintegration of clinical empathy will prove beneficial to the experience of the autistic patient as they navigate the emergency department. It is critical in the utilization of autism care ethics by providers as they work to care for them in a patient-centered and trauma-informed manner. Empathy is a crucial component of the physician-patient relationship and many of the factors that guide care ethics. A a lack of clinical empathy and the promotion of detachment on behalf of providers may explain why so many of these abhorrent behaviors have continued in department specific protocols and in practice.

Chapter 5: Disposition & Visit Summary: A New Lens and Future Directions

Autism care ethics presents healthcare care workers (both nurses and physicians alike) with the opportunity to revisit the way in which they approach care for the autistic patient in the emergency department. The needs of the autistic patient vary and the autistic experience is not fully understood, especially by those who are neurotypical. In the dynamic environment of the emergency department, it is essential that care teams do not prioritize efficiency over the need to meet the specific and unique needs of the autistic patient. A care plan situated in autism care ethics will ensure patient-centered and trauma-informed care that meets the diverse needs of the autistic patient in the emergency department through relationship-building and detail-orientation.

The newly introduced paradigm of autism care ethics is rooted in the concept of care ethics, relying on foundational concepts put forth by Gilligan and Noddings. Factors such as "engrossment" and attention to the "fine details" are aspects of these theories that can be combined within autism care ethics to deliver patient-centered care to the autistic child (Gilligan 1982, Noddings 1984). Relying on the work of McCabe (2008), the synthesis of Gilligan and Noddings' foundational work was complemented with the work of Slote (2001) and Manning (1992) to make care ethics applicable to the field of medicine.

The concept of autism care ethics was proposed and reviewed in the context of previously identified issues in the care of autistic patients in the pediatric ED. An added element of the work of Jodi Halpern was then utilized to highlight the current lack of clinical empathy in medicine and the detriment that this has had in the care of autistic patients (2003). A quote by Dr. Francis Peabody was particularly illuminating in light of the connection to common themes of care, empathy, and the problems facing care for the autistic population in the emergency department.

"One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient."

Dr. Francis Peabody, MD – "The Care of the Patient" (JAMA 1927)

Dr. Peabody's quote regarding humanity and the art of caring summed up the paradigm shift that is necessary in order to adopt this new theory. A paradigm of autism care ethics that would deliver ethically minded care to the autism community in the pediatric emergency department and beyond. As Dr. Peabody described, there is a strong desire of the clinician to positively impact humanity through care for their patients. It is no secret that this positive impact in care for the patient, rests in the art of caring.

This work could be enhanced through attempting to capture the first-hand accounts of the autistic experience in the emergency department for the further development of autism care ethics. A potential limitation of autism care ethics is that it strongly based in the perspectives of those who interact with autistic persons (medical professionals, academic professionals, and caregivers), rather than the perspectives of autistic patients themselves. It is important to begin to integrate autistic voices into the discussion and the development of this theory, in order to consider the lived experience of those with autism. Autism care ethics has great opportunity for further development and the potential to be applied in areas outside of medicine. The concept of autism care ethics should be translated to other fields where care ethics has been implemented such as in education. Additionally, autism care ethics is translatable to other fields of medicine and could readily be applied to inpatient psychiatric units, general pediatrics floors, the pediatric intensive care unit, and the pediatrician's office.

This work serves to lay the foundation for considerations of how autistic individuals are treated by and how they navigate the medical system. This paradigm will further conversations in restoring empathy in care while prioritizing patient-centered and trauma informed care-plans for the autism community. While neurotypical providers may not understand the autistic experience, they should make an effort to inform the care that they deliver. While caring and curing may be a matter of semantics, empathetic patient-centered care has the potential to transform medicine.

References

Aacharya, R. P., Gastmans, C., & Denier, Y. (2011). Emergency department triage: an ethical analysis. BMC emergency medicine, 11, 1-13.

Aljohani, B., Burkholder, J., Tran, Q. K., Chen, C., Beisenova, K., & Pourmand, A. (2021). Workplace violence in the emergency department: a systematic review and meta-analysis. Public health, 196, 186-197.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Aschen, S. R. (1995). Restraints: Does position make a difference?. Issues in Mental Health Nursing, 16(1), 87-92.

Beauchamp, T. L., & Childress, J. F. (2001). Principles of biomedical ethics. Oxford University Press, USA.

Bindner, A., Hardin, A. O., & Berkenbosch, J. W. (2008). Pediatric intensive care unit management and discharge of a severely autistic patient. Internet J Emerg Intensive Care Med, 11(2).

Boles, J. M., Maccarone, D., Brown, B., Archer, A., Trotter, M. G., Friedman, N. M., ... & Cacchione, P. Z. (2023). Nurse, provider, and emergency department technician: Perceptions and experiences of violence and aggression in the emergency department. Journal of emergency nursing, 49(3), 431-440.

Burgess, L., & Kynoch, K. (2017). Effectiveness of nurse-initiated interventions on patient outcomes in the emergency department: a systematic review protocol. JBI Evidence Synthesis, 15(4), 873-881.

Caffy, K., Jones, T. L., & Gilmore, B. G. (2019). A collaborative behavioral model for psychiatric visits in a pediatric emergency department. Pediatric Emergency Care, 35(7), 461-467.

Cassel E. J. (1982). The nature of suffering and the goals of medicine. The New England journal of medicine, 306(11), 639–645. https://doi.org/10.1056/NEJM198203183061104

Chang, B. P., Cato, K. D., Cassai, M., & Breen, L. (2019). Clinician burnout and its association with team based care in the Emergency Department. The American journal of emergency medicine, 37(11), 2113.

Chun, T. H. (2014). Medical clearance: time for this dinosaur to go extinct. Annals of Emergency Medicine, 63(6), 676-677.

Chun, T. H., Mace, S. E., Katz, E. R., American Academy of Pediatrics, Committee on Pediatric Emergency Medicine, & American College of Emergency Physicians. (2016). Evaluation and management of children and adolescents with acute mental health or behavioral problems. Part I:

common clinical challenges of patients with mental health and/or behavioral emergencies. *Pediatrics*, *138*(3).

Costa, A. P., Loor, C., & Steffgen, G. (2020). Suicidality in adults with autism spectrum disorder: the role of depressive symptomatology, alexithymia, and antidepressants. Journal of autism and developmental disorders, 50(10), 3585-3597.

Cutler, G. J., Rodean, J., Zima, B. T., Doupnik, S. K., Zagel, A. L., Bergmann, K. R., ... & Neuman, M. I. (2019). Trends in pediatric emergency department visits for mental health conditions and disposition by presence of a psychiatric unit. Academic pediatrics, 19(8), 948-955.

de Bruin, E. I., Ferdinand, R. F., Meester, S., de Nijs, P. F., & Verheij, F. (2007). High rates of psychiatric co-morbidity in PDD-NOS. Journal of autism and developmental disorders, 37, 877-886.

DeFilippis, M. (2018). Depression in children and adolescents with autism spectrum disorder. Children, 5(9), 112.

Dolan, M. A., Fein, J. A., & Committee on Pediatric Emergency Medicine. (2011). Pediatric and adolescent mental health emergencies in the emergency medical services system. Pediatrics, 127(5), e1356-e1366.

Donofrio, J. J., Santillanes, G., McCammack, B. D., Lam, C. N., Menchine, M. D., Kaji, A. H., & Claudius, I. A. (2014). Clinical utility of screening laboratory tests in pediatric psychiatric patients presenting to the emergency department for medical clearance. Annals of emergency medicine, 63(6), 666-675.

Dorfman, D. H., & Kastner, B. (2004). The use of restraint for pediatric psychiatric patients in emergency departments. Pediatric emergency care, 20(3), 151-156.

Dorfman, D. H., & Mehta, S. D. (2006). Restraint use for psychiatric patients in the pediatric emergency department. Pediatric emergency care, 22(1), 7-12.

Eldridge, C., & Kennedy, R. (2010). Nonpharmacologic techniques for distress reduction during emergency medical care: a review. Clinical Pediatric Emergency Medicine, 11(4), 244-250.

Foster, A. A., Saidinejad, M., Duffy, S., Hoffmann, J. A., Goodman, R., Monuteaux, M. C., & Li, J. (2023). Pediatric agitation in the emergency department: A survey of pediatric emergency care coordinators. *Academic pediatrics*, *23*(5), 988-992.

Funderburke, P. (2008). Exploring best practice for triage. Journal of Emergency Nursing, 34(2), 180-182.

Gerson, R., Malas, N., Feuer, V., Silver, G. H., Prasad, R., & Mroczkowski, M. M. (2019). Best practices for evaluation and treatment of agitated children and adolescents (BETA) in the emergency department: consensus statement of the American Association for Emergency Psychiatry. Western Journal of Emergency Medicine, 20(2), 409.

Halpern, J. (2003). What is clinical empathy?. Journal of general internal medicine, 18, 670-674.

Hazen, E. P., Ravichandran, C., Rao Hureau, A., O'Rourke, J., Madva, E., & McDougle, C. J. (2020). Agitation in patients with autism spectrum disorder admitted to inpatient pediatric medical units. Pediatrics, 145(Supplement_1), S108-S116.

Hazen, E. P., McDougle, C. J., & Volkmar, F. R. (2013). ASCP Corner: Changes in the Diagnostic Criteria for Autism in DSM-5: Controversies and Concerns. The Journal of clinical psychiatry, 74(7), 1387.

Hens, K., Robeyns, I., & Schaubroeck, K. (2019). The ethics of autism. Philosophy Compass, 14(1), e12559.

Horowitz LM, Bridge JA, Teach SJ, et al. Ask Suicide-Screening Questions (ASQ): A Brief Instrument for the Pediatric Emergency Department. *Arch Pediatr Adolesc Med.* 2012;166(12):1170–1176. doi:10.1001/archpediatrics.2012.1276

Hossain, M. M., Khan, N., Sultana, A., Ma, P., McKyer, E. L. J., Ahmed, H. U., & Purohit, N. (2020). Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: An umbrella review of systematic reviews and meta-analyses. Psychiatry research, 287, 112922.

Hurley, D.P., Pavlov, A.C., Pattishall, A.E., Call, N.A., Morris, C.R. (Forthcoming). Medically unnecessary and unethical venipuncture for autism spectrum behavior assessments. Forthcoming.

Iannuzzi, D. A., Cheng, E. R., Broder-Fingert, S., & Bauman, M. L. (2015). Brief report: Emergency department utilization by individuals with autism. *Journal of Autism and Developmental Disorders*, *45*, 1096-1102.

Isaksen, J., Bryn, V., Diseth, T. H., Heiberg, A., Schjølberg, S., & Skjeldal, O. H. (2013). Children with autism spectrum disorders–the importance of medical investigations. European Journal of Paediatric Neurology, 17(1), 68-76.

Jecker, N. S., & Self, D. J. (1991). Separating care and cure: an analysis of historical and contemporary images of nursing and medicine. The Journal of medicine and philosophy, 16(3), 285-306.

Kairys, S. W., & Petrova, A. (2016). Role of participation of pediatricians in the "Activated Autism Practice" program in practicing children with autism spectrum disorders at the primary care setting. Global Pediatric Health, 3, 2333794X16663544.

Kalb, L. G., Stuart, E. A., Freedman, B., Zablotsky, B., & Vasa, R. (2012). Psychiatric-related emergency department visits among children with an autism spectrum disorder. *Pediatric Emergency Care*, *28*(12), 1269-1276.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous child*, *2*(3), 217-250.

Key components of safety. APNA. (2022, March 30). https://www.apna.org/key-components-of-safety/

Kopecky, K., Broder-Fingert, S., Iannuzzi, D., & Connors, S. (2013). The needs of hospitalized patients with autism spectrum disorders: a parent survey. Clinical Pediatrics, 52(7), 652-660.

Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., ... & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. The Lancet Psychiatry, 6(10), 819-829.

Lo, C. B., Bridge, J. A., Shi, J., Ludwig, L., & Stanley, R. M. (2020). Children's mental health emergency department visits: 2007–2016. Pediatrics, 145(6).

Lord, C., Elsabbagh, M., Baird, G., & Veenstra-Vanderweele, J. (2018). Autism spectrum disorder. *The lancet*, *392*(10146), 508-520.

Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveill Summ 2023;72(No. SS-2):1–14. DOI: http://dx.doi.org/10.15585/mmwr.ss7202a1.

Mahajan, P., Alpern, E. R., Grupp-Phelan, J., Chamberlain, J., Dong, L., Holubkov, R., ... & Pediatric Emergency Care Applied Research Network. (2009). Epidemiology of psychiatric-related visits to emergency departments in a multicenter collaborative research pediatric network. Pediatric emergency care, 25(11), 715-720.

Martinsen, E. (2011). Harm in the absence of care: Towards a medical ethics that cares. Nursing ethics, 18(2), 174-183.

Martinsen, E. H. (2011). Care for nurses only? Medicine and the perceiving eye. *Health Care Analysis*, *19*(1), 15-27.

Mazzone, L., Postorino, V., Siracusano, M., Riccioni, A., & Curatolo, P. (2018). The relationship between sleep problems, neurobiological alterations, core symptoms of autism spectrum disorder, and psychiatric comorbidities. Journal of clinical medicine, 7(5), 102.

McDermid, F., Mannix, J., & Peters, K. (2020). Factors contributing to high turnover rates of emergency nurses: A review of the literature. Australian critical care, 33(4), 390-396.

McGonigle, J. J., Migyanka, J. M., Glor-Scheib, S. J., Cramer, R., Fratangeli, J. J., Hegde, G. G., ... & Venkat, A. (2014). Development and evaluation of educational materials for pre-hospital and emergency department personnel on the care of patients with autism spectrum disorder. Journal of Autism and Developmental Disorders, 44, 1252-1259.

Miller, D., Walker, M. C., & Friedman, D. (1989). Use of a holding technique to control the violent behavior of seriously disturbed adolescents. Psychiatric Services, 40(5), 520-524.

Mroczkowski, M. M., & Havens, J. (2018). The state of emergency child and adolescent psychiatry: raising the bar. Child and Adolescent Psychiatric Clinics, 27(3), 357-365.

Mullan, P. C., Levasseur, K. A., Bajaj, L., Nypaver, M., Chamberlain, J. M., Thull-Freedman, J., Ostrow, O., & Jain, S. (2024). Recommendations for Choosing Wisely in Pediatric Emergency

Medicine: Five Opportunities to Improve Value. Annals of emergency medicine, S0196-0644(24)00017-9. Advance online publication. https://doi.org/10.1016/j.annemergmed.2024.01.007

Nadler, A., Avner, D., Khine, H., Avner, J. R., & Fein, D. M. (2021). Rising clinical burden of psychiatric visits on the pediatric emergency department. Pediatric emergency care, 37(1), 1-3.

National Institute of Mental Health. (2024). Autism Spectrum Disorder (NIMH Identifier No. OM 0925-0648). U.S. Department of Health and Human Services, National Institutes of Health. Retrieved February 11, 2024, from https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd

Nelson, H. L. (1992). Against caring. *The Journal of Clinical Ethics*, *3*(1), 8-15.

Noddings, N. (1992). In defense of caring. *The journal of clinical Ethics*, *3*(1), 15-18.

Oakley, B., Loth, E., & Murphy, D. G. (2021). Autism and mood disorders. International Review of Psychiatry, 33(3), 280-299.

O'Halloran, L., Coey, P., & Wilson, C. (2022). Suicidality in autistic youth: A systematic review and meta-analysis. Clinical Psychology Review, 93, 102144.

Olsen, D. P. (1998). Toward an ethical standard for coerced mental health treatment: least restrictive or most therapeutic?. *The Journal of Clinical Ethics*, *9*(3), 235-246.

Osler W., (1963) Aequanitmitas. New York, NY: Norton, 29

Park, H. R., Lee, J. M., Moon, H. E., Lee, D. S., Kim, B. N., Kim, J., ... & Paek, S. H. (2016). A short review on the current understanding of autism spectrum disorders. *Experimental neurobiology*, *25*(1), 1.

Peabody FW. The Care of the Patient. *JAMA.* 1927;88(12):877–882. doi:10.1001/jama.1927.02680380001001

Reich, W. T. (1995). Classic Article:" History of the Notion of Care., Encyclopedia of Bioethics.

Saidinejad, M., Duffy, S., Wallin, D., Hoffmann, J. A., Joseph, M. M., Schieferle Uhlenbrock, J., ... & EMERGENCY NURSES ASSOCIATION Pediatric Committee. (2023). The management of children and youth with pediatric mental and behavioral health emergencies. Pediatrics, 152(3).

Sakai, C., Miller, K., Brussa, A. K., MacPherson, C., & Augustyn, M. (2014). Challenges of autism in the inpatient setting. *Journal of Developmental & Behavioral Pediatrics*, *35*(1), 82-84.

Sampson, F. C., Goodacre, S. W., & O'cathain, A. (2014). Interventions to improve the management of pain in emergency departments: systematic review and narrative synthesis. Emergency Medicine Journal, 31(e1), e9-e18.

Santiago, L. I., Tunik, M. G., Foltin, G. L., & Mojica, M. A. (2006). Children requiring psychiatric consultation in the pediatric emergency department: epidemiology, resource utilization, and complications. Pediatric emergency care, 22(2), 85-89.

Santillanes, G., Rowland, K., Demarest, M., Lam, C. N., Wilson, M. P., Claudius, I., & Menchine, M. (2020). Discontinuing involuntary mental health holds for children: Does psychiatrist specialty matter? A pilot study. *The American Journal of Emergency Medicine*, *38*(4), 702-708.

Scarpinato, N., Bradley, J., Kurbjun, K., Bateman, X., Holtzer, B., & Ely, B. (2010). Caring for the child with an autism spectrum disorder in the acute care setting. Journal for Specialists in Pediatric Nursing, 15(3), 244-254.

Sheridan, D. C., Sheridan, J., Johnson, K. P., Laurie, A., Knapper, A., Fu, R., ... & Hansen, M. L. (2016). The effect of a dedicated psychiatric team to pediatric emergency mental health care. The Journal of Emergency Medicine, 50(3), e121-e128.

Straus, J., Coburn, S., Maskell, S., Pappagianopoulos, J., & Cantrell, K. (2019). Medical encounters for youth with autism spectrum disorder: a comprehensive review of environmental considerations and interventions. Clinical Medicine Insights: Pediatrics, 13, 1179556519842816.

Stricker, F. R., O'Neill, K. B., Merson, J., & Feuer, V. (2018). Maintaining safety and improving the care of pediatric behavioral health patients in the emergency department. Child and adolescent psychiatric clinics of North America, 27(3), 427-439.

Taboas, A., Doepke, K., & Zimmerman, C. (2023). Preferences for identity-first versus person-first language in a US sample of autism stakeholders. Autism, 27(2), 565-570. https://doi.org/10.1177/13623613221130845

Thom, R. P., Hazen, M. M., McDougle, C. J., & Hazen, E. P. (2020). Providing inpatient medical care to children with autism spectrum disorder. Hospital pediatrics, 10(10), 918-924.

Tuchman, R., & Rapin, I. (2002). Epilepsy in autism. The Lancet Neurology, 1(6), 352-358.

Vaz, I. (2013). Visual symbols in healthcare settings for children with learning disabilities and autism spectrum disorder. British Journal of Nursing, 22(3), 156-159.

Walker, T. (2009). What principlism misses. *Journal of Medical Ethics*, *35*(4), 229-231.

Wharff, E. A., Ginnis, K. B., Ross, A. M., & Blood, E. A. (2011). Predictors of psychiatric boarding in the pediatric emergency department: implications for emergency care. Pediatric Emergency Care, 27(6), 483-489.

Wing, L. (1981). Language, social, and cognitive impairments in autism and severe mental retardation. *Journal of autism and developmental disorders*, *11*(1), 31-44.

Wittling, K., Dufur, J. P., McClain, A., & Gettis, M. (2018). Behavioral coping plans: One inter-professional team's approach to patient-centered care. Journal of Pediatric Nursing, 41, 135-139.

Zicko, C. J. M., Schroeder, L. R. A., Byers, C. W. S., Taylor, L. A. M., & Spence, C. D. L. (2017). Behavioral emergency response team: implementation improves patient safety, staff safety, and staff collaboration. *Worldviews on Evidence-Based Nursing*, *14*(5), 377-384.

Acknowledgements

This project is the culmination of many long nights working in the pediatric emergency department while pursuing my undergraduate degree at Emory University. A setting which opened my eyes to many of the issues that we currently face in medicine. Their intersections with ethics and public health have allowed me to find my passion in medicine.

To my entire thesis committee, for their efforts in making this project impactful and thoughtful in every way possible.

To my teachers, professors, professional mentors, and family that have believed in me and my many interests and passions.

To Kathy Kinlaw, for her dedication to transforming a simple brainstorming session to this final work.

To Dr. April Dworetz, for her insightful critiques and guidance in academic writing.

To Dr. Claudia Morris, for her years of mentorship and for the opportunity to explore this issue in depth in order to grow as a young academic researcher, ethicist, and future physician.

To my undergraduate mentor, Dr. Michelle Lampl, for igniting a passion that the art of medicine exists beyond simply the biomedical.

To my Grady Ethics Family (Dr. Maura George & Elizabeth Sivertsen), for believing in me and giving me the opportunity to explore clinical ethics at Grady.

To my lovely wife Casey and young daughter Charlie, for accompanying me on this journey. Although the road may be long, it will be worth it. I do it all for you.