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SEVERE BEHAVIOR AND RESTRAINT USE IN A HOSPITAL SETTING FOR PATIENTS WITH AUTISM SPECTRUM DISORDER

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Abstract

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Physicians in hospital settings are treating an increasing number of patients with autism spectrum disorder (ASD). The occurrence of severe behavior is heightened for patients with ASD in hospital settings. Restraint is a commonly cited strategy to manage severe behavior across hospital departments; however, research on physician management of severe behavior in patients with ASD across the lifespan is lacking. Our sample included 25 participants across three medical trainee focus groups and three physician interviews. We investigated their experiences with severe behavior management and restraint implementation in patients with ASD at an urban teaching hospital. Transcripts were thematically analyzed using the constant comparative method of qualitative data analysis. Twenty themes emerged from participant narratives on experiences with severe behavior in patients with ASD. The five most salient themes included: (1) implementation of restraint by other hospital professionals and a lack of procedural knowledge; (2) alternative strategies to manage severe behavior in patients with ASD; (3) negative reactions/perceptions of restraint; (4) the helpful role of caregivers in treating patients with ASD; and (5) limited practical experience treating patients with ASD. Questionnaire results indicated adequate knowledge of ASD, with higher knowledge scores and lower reported stigma in physician participants.

Keywords: restraint, autism spectrum disorder, severe behavior, hospital

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Chapter 1

Introduction

In the United States, an estimated 1 in 54 individuals present with autism spectrum disorder (ASD; Baio et al., 2018). Severe behavior, such as aggression, self-injury, and property destruction, is highly prevalent in individuals with ASD as compared to their neurotypical peers (Newcomb & Hagopian, 2018). Although severe behavior is common in individuals with ASD, prevalence estimates of severe behavior vary widely across the literature. Hill et al. (2014) estimated that the prevalence of aggressive and destructive behavior in children with ASD ranges from 8% to 68%. Other researchers have described the prevalence of challenging behavior in children with ASD as high as 82% (Murphy et al., 2009) to 93.7% (McTiernan et al., 2011). This discrepancy has been attributed to differing operational definitions of severe behavior, assessments used, and study participants. Kanne and Mazurek (2011) found that prevalence estimates of severe behavior were higher when based on parental report using rating scale measures such as the Repetitive Behavior Scale–Revised (Lam & Aman, 2007) and Social Responsiveness Scale (Constantino et al., 2003) as compared to standardized interview measures, such as the Autism Diagnostic Interview–Revised (Rutter et al. 2003). Further, the majority of research on the prevalence of severe behavior is limited to children.

Individuals with ASD who engage in severe behavior and their families are often faced with significant challenges. Severe behavior can cause injury to themselves and others, and cause damage to property (Kanne & Mazurek, 2011; Newcomb & Hogopian, 2018). Severe behavior has the potential to impair social relationships with one's peers, family and community members, and may also lead to social stigmatization (Werner &

Shulman, 2013). In addition, those with ASD and comorbid severe behavior often require a higher level of care and additional services as compared to individuals with ASD without severe behavior. It is likely that individuals with ASD who engage in severe behavior require increased services, spanning multiple categories including healthcare, education, residential, habilitative, and vocational, which are likely to be high in cost (Buescher et al., 2014; Hill et al., 2014). Finally, an individual's severe behavior may interfere with skill acquisition and on-task behavior, which may ultimately affect one's educational and vocational status and attainment (Deavenport-Saman et al., 2016; Emerson et al., 2001).

Furthermore, research suggests that restraint is implemented more frequently for those with intellectual and developmental disabilities than their neurotypical peers (Friedman & Crabb, 2018; Newcomb & Hogopian, 2018; O'Donoghue et al., 2020). Restraint is described as a restrictive behavior management strategy that can be grouped into categories of physical, mechanical, and chemical restraint. Physical restraint refers to at least one person restricting an individual's ability to move freely, such as positioning one's body to restrict an individual's movement of torso, arms, legs, or head. Mechanical restraint refers to the use of any device or equipment to restrict movement, such as applying arm splints or waist straps. Finally, chemical restraint refers to the use of pharmacological means (e.g., Benzodiazepines) with the intent to inhibit patient movement and manage emergent behaviors outside of prescribed standard of care treatment (Friedman & Crabb, 2018). Restraint can be implemented both reactively to manage emergent behaviors and proactively to facilitate medical compliance and access to medical care (Allen et al., 2009; Kupzyk & Allen, 2019).

Within school settings, restraint is used at disproportionate rates with individuals with disabilities (Barnard-Brak et al., 2014; Gage, 2020). A review of 101,990 students restrained between 2017-2018 found that 78% of students restrained were students with disabilities (US Department of Education, Office of Civil Rights, 2020). Researchers emphasized the need for school settings to find balance between managing severe behavior with restraint for safety purposes and maintaining a safe learning environment. A record review examining the U.S. Department of Education's Office of Civil Rights data from the 2015-2016 academic year indicated that students with developmental disabilities are seven times more likely to be physically restrained than their peers (Gage, 2020). These disproportionate rates of restraint may be due to higher incidence of severe behavior in students with intellectual disabilities (Matson & Boisjoli, 2009). Thus, research must examine the overall incidence of severe behavior to determine whether schools are more likely to restrain students with disabilities following the occurrence of severe behavior. Barnard-Brak and colleagues (2014) established several factors that contribute to disproportionate restraint use in school settings, such as state regulations, socioeconomic status, and student demographics. Specifically, public schools within states that did not regulate the use of restraint had more reported restraint events than those that did regulate restraint use. Schools with lower socioeconomic status (SES), as determined by free or reduced lunch status, reported higher restraint use. In addition, student demographics and age were indicated as covariates to restraint use. Schools with a higher percentage of white, non-Hispanic students were more likely to report zero instances of restraint. Finally, students in high school were more likely to experience zero reported restraint events. Thus, these researchers concluded that schools with younger

students of lower SES and located within a state that regulates restraint use are more likely to report restraint events (Barnard-Brak et al., 2014). Given these statistics, service providers for individuals with ASD warrant additional support, training, and education to deliver optimal educational services to all students with disabilities (U.S. Department of Education, 2019).

In addition to the educational setting, restraint use is also common with individuals with ASD who engage in severe behavior in institutional, residential, day habilitation, and vocational settings. Recent research documented that use of physical restraint was almost always permitted in institutional and residential settings, with use of chemical and mechanical restraint less frequently permitted (Friedman & Crabb, 2018). Alternative approaches and initiatives to reduce restrictive behavior management, such as staff training, reformed organizational policies, and mindfulness-based interventions, have recently received attention in the literature. Such initiatives to reduce restraint implementation have been associated with positive outcomes across various settings, including improved safety for staff and individuals with developmental disabilities and decreased long-term costs (Sturmey, 2018).

Further, restraint is one commonly reported strategy to manage severe behavior in patients with ASD in hospital settings (Johnson & Rodriquez, 2013; Lunsky et al., 2014; O'Donoghue et al., 2020). A systematic review indicated that although healthcare professionals identified alternative strategies to restraint (e.g., clear communication, visual cues), restraint is commonly used to manage challenging behavior and assist in the completion of medical procedures for children with ASD within inpatient settings (Johnson & Rodriquez, 2013). Within a sample of children hospitalized within a

psychiatric unit, 52% of children experienced restraint, and children with a diagnosis of ASD and intellectual disability experienced higher rates of restraint compared to those without those diagnoses (O'Donoghue et al., 2020). Parental report indicated that sedation and/or physical restraint were used during 23% of emergency department visits for adolescent and adult patients with ASD (Lunsky et al., 2014). Taken together, research on hospital restraint with individuals with ASD has primarily focused on pediatric patients within specific departments or settings.

Although research has demonstrated that restraint is often used in hospital settings to manage severe behavior, the strategies physicians use to manage severe behavior in patients with ASD remain unclear. Research has largely focused on record review or self-report measures and has not explored physicians' experiences with severe behavior management in patients with ASD across the lifespan. Physicians are required to abide by medical association and institutional policies of restraint (Blumberg & Roppolo, 2021; Johnson & Rodriguez, 2013). According to Blumberg and Roppolo (2021), the American College of Emergency Physicians (ACEP) outlines a sequence of steps to follow with regard to restraint implementation, such as physicians first attempting verbal de-escalation, adhering to applicable laws and regulations, and the institutions providing training to staff implementing restraints. The Joint Commission on Accreditation of Healthcare Organizations (2010) has also provided standards regarding restraint; however, these standards are specific to physical restraint. As recognized by the organization, the enforcement of these policies is largely contingent upon hospital policies.

Blumberg and Roppolo (2021) caution physicians that restraint should only be used after all other safer alternatives have been exhausted and when necessary to ensure the safety of patients and others due to the potential of adverse effects. Such adverse effects of restraint vary by restraint type. Mechanical restraint may result in skin breakdown and difficulties with balance, strength, and gait, loss of muscle mass, and infection (Evans & Cotter, 2008). More significantly, adverse effects of physical or chemical restraint use can include serious injury, death, functional decline, and increased risk of depression, anxiety, and post-traumatic stress disorder. Prior to and following the use of physical restraint, adult emergency department patients with a range of presenting concerns (e.g., substance use, mental health concerns) reported distrust of medical professionals and a lack of autonomy in making decisions regarding their own medical care (Wong et al., 2020). One hospital system aimed to reduce physical restraint use by including more expansive training and education, goal-setting across departments, multidisciplinary rounds, and alternative equipment (e.g., soft belts, arm sleeves). Authors demonstrated the successful reduction of restraint and a drastic culture shift in how medical providers viewed and used restraint within a hospital system, showing clear promise for other hospital systems (Cosper et al., 2015).

Roy and colleagues (2019) demonstrated the following predictors of restraint implementation in healthcare settings: (a) patient characteristics (e.g., sex, age, diagnosis, nationality); (b) the care provider and team (e.g., education, experience, stress, attitudes toward mental illness); (c) the organization (e.g., promotion of continuing education/training, documentation of behaviors, values/norms); and (d) the environment (e.g., smaller physical space). Researchers describe that the decision to implement

restraint is multifactorial, with various factors (e.g., patient characteristics, organization) interacting to make a split-second decision of whether to restrain a patient.

The majority of studies exploring variables influencing restraint implementation have focused on general populations not specific to patients with ASD. Within hospital patients without an ASD diagnosis, a patient's age, ethnicity, and gender have been reported to influence a healthcare provider's decision to use restraint (Grimes et al., 2012; Mann-Poll et al., 2011). Younger patient age and higher perceived patient impulsivity led to higher restraint usage within a psychiatric setting (Grimes et al., 2012). In partial agreement with that finding, a review by Larue et al. (2009) demonstrated that restraint was more commonly applied within young and middle-aged patients as compared to elderly patients due to perceived risk of danger to others. These findings suggest that healthcare providers are more likely to respond reactively with restraint implementation due to perceived danger. Within an emergency department setting, an overwhelming majority of patients restrained were African American men (Zun, 2003). Wong et al. (2019) also conducted research in one emergency department, demonstrating that a majority of all patients restrained were male (66.7%; median age = 47 years). Common presentations that led to restraint use included alcohol or drug use, medical, psychiatric, and trauma. A majority of patients restrained were perceived as a danger to self or others (60.6%) or non-compliant or unwilling to follow directions (28.1%; Wong et al., 2019). As it appears in the literature, specific patient presentations may be perceived as more threatening to healthcare providers, and thus, lead to disproportionate restraint use. Although these studies present valuable information on predictors of restraint, research

has not specifically focused on patients with ASD whose acute medical care needs might differ.

The literature has also begun to investigate physician training and ASD-specific experiences, including their knowledge of ASD diagnostic features, and perceived competency and comfort treating patients with ASD. In one study specific to pediatric patients with ASD and intellectual disability, researchers reported an increased risk of inappropriate restraint use due to limited staff training and knowledge of ASD (Gabriels et al., 2011). Zerbo et al. (2015) demonstrated that a majority of healthcare providers reported their knowledge and practical skills in treating patients with ASD as poor or fair. One physician reported knowledge of ASD from previous coursework but lacked direct training in managing patients with ASD. There were also detected differences by the type of provider with mental health providers having more knowledge and skills compared to providers of adult medicine and OBGYN services. In another study conducted with adult neurologists, participants reported less comfort treating adult patients with ASD than those with other neurological disorders (Oskoui & Wolfson, 2012). Similarly, pediatric and family physicians reported lower self-perceived competency treating children with ASD than those with other neurodevelopmental disorders (Golnik & Borowsky, 2009). Overall, these deficits in knowledge and lower physician confidence treating patients with ASD could contribute to their overreliance on restraint to manage severe behavior.

The gap in physician knowledge and perceived competency is concerning as it may affect physicians' delivery of safe and effective treatment to patients with ASD. In the field of applied behavior analysis, functional analysis (FA) is the gold standard approach to informing treatment of severe behavior. Treatments for severe behavior

informed by FAs target behavioral function. Common functions of severe behavior include access to attention, escape from aversive tasks or stimuli, sensory stimulation (Iwata et al., 1982/1994), access to a tangible item (Day et al., 1988), and routine restoration (Hagopian et al., 2007). For example, if an individual's severe behavior is maintained by access to attention, rates of severe behavior may increase during a hospital visit due to a decrement in amount and quality of attention provided as compared to attention received in other settings. Further, an individual with an escape function may engage in severe behavior during scheduled procedures to escape the anxiety-provoking and unfamiliar situation. Function-based treatments are widely studied and are documented as more effective in producing improved behavioral outcomes than non-function-based treatments (Campbell, 2003; Heyvaert et al., 2014). Given the documented effectiveness of function-based treatment, it is crucial for physicians to understand the function of severe behavior. Physician understanding and application of function-based assessment and treatment could mitigate restraint use across hospital departments and optimize care for patients with ASD.

As the prevalence of ASD continues to increase in the United States (Christensen et al., 2019), healthcare providers are likely to treat more patients with an ASD diagnosis. Hospital settings can be particularly challenging for individuals with ASD across the lifespan due to core features of ASD, such as social communication challenges, sensory sensitivity, and routine rigidity (American Psychiatric Association, 2013). A patient in a hospital setting may encounter unfamiliar physicians, bright lights, loud noises, crowded spaces, and unpredictable routines that can evoke severe behavior. In addition, hospitals present many communication requirements that can be challenging for patients with ASD

who present with communication difficulties (Broder-Fingert et al., 2015). Increased

frustration surrounding communication with healthcare providers may contribute to the

occurrence of severe behavior. Communication challenges may also contribute to

physician difficulty understanding and interpreting pain, physical discomfort, or signs

and symptoms of medical conditions in patients with ASD (Broder-Fingert et al., 2015).

As a result, autism-specific care plans (ACPs) are an emerging research area aimed to

improve experiences of care for both the individual with ASD and their family (Broder-

Fingert et al., 2015). These ACPs include information regarding communication

preferences and strategies, environmental modifications, and safety concerns. Care plans

are created by parents and available to physicians through the patient's electronic medical

record or by hard copy. Care plans have previously been used with various presenting

concerns in hospital systems, such as chronic care (van Dongen et al., 2016), cancer

(Jacobsen et al., 2018), and emergency preparedness (Rathlev et al., 2016). Broder-

Fingert et al. (2015) extended the use of care plans to the unique needs of patients with

ASD during their hospital stay. Results demonstrated the feasibility of ACPs for

improving the experience of pediatric patients with ASD and their families. However,

physician's use of ACPs for treating patients with ASD across the lifespan and their

efficacy across various hospital departments and diverse gender and racial populations

has not been established (Broder-Fingert et al., 2015).

Individuals with ASD disproportionately use hospital services as compared to

their peers. Research has indicated that adolescents with ASD alone are four times more

likely to visit emergency rooms annually than their neurotypical peers (Liu et al., 2017).

This high rate of hospitalization may be indicative of heightened healthcare needs. An

ASD diagnosis is highly comorbid with medical and psychiatric concerns (e.g., anxiety, depression, and gastrointestinal symptoms) which may necessitate emergency medical services (Lunsky et al., 2014; van Steensel et al., 2011). Lunsky and colleagues (2014) also deemed history of severe behavior as a contributing factor to hospital overutilization among patients with ASD. Although most presenting concerns for patients with ASD in emergency departments have been classified as medical (65.4%), the second main classification is mental health (34.6%). Mental health visits are defined as concerns regarding psychiatric or behavioral issues, with aggression accounting for one-third of the mental health visits in this study. Further, although a majority of hospital admissions were originally classified as medical, parental report indicated associated behavioral issues during their child's hospital stay. For instance, one patient in this study engaged in severe head banging that required stitches due to perceived frustration while another patient engaged in aggression due to an undetected urinary tract infection at the time of the medical evaluation (Lunsky et al., 2014). Thus, presenting medical concerns alone may not predict the level of care an individual with ASD and comorbid severe behavior requires during their hospital stay. Instead, hospitals must be proactive in ASD-specific needs and prepared to appropriately manage the occurrence of severe behavior.

Teaching hospitals hold significant importance in the healthcare field because they provide medical education and training to the next generation of doctors. However, the procedures to manage severe behavior among patients with ASD in teaching hospitals have received less attention in the literature. Miner and colleagues (2018) examined the prevalence of restraint use at one Level 1 trauma center emergency department for a variety of patients described as agitated. These researchers reported that 84% of adult

patients who engaged in severe behavior were physically restrained, 72% were chemically sedated, and both types of restraint were applied for several patients (1.8%; Miner et. al, 2018). Research suggests that rates of hospitalization of patients with ASD are highest at large, urban teaching hospitals in the Northeastern United States (Lokhandwala et al., 2012). Taken together, safe and effective treatment procedures for treating patients with ASD are critically needed across the United States and urban teaching hospitals in the Northeast are an ideal location to conduct this research.

The current study seeks to extend the literature on management of severe behavior in hospital patients with ASD by exploring physician experiences treating patients with ASD across the lifespan who engage in severe behavior. As most of the established literature on restraint occurrence and predictive variables is focused on those without ASD or pediatric patients with ASD, this study extends the literature to all patient ages and across hospital departments likely to treat patients with ASD. Although the literature has established predictors of restraint, gaps exist in who commonly implements a restraint and the reason for restraint use, and physician experiences managing severe behavior using alternative approaches to restraint. Decreased competency and perceived comfort treating patients with ASD has been demonstrated; however, this study explores medical training and perceived needs that may impact the quality of healthcare delivery to patients with ASD who engage in severe behavior. In this study, multidisciplinary focus groups and interviews were conducted to gather preliminary data from medical trainees and early-career physicians on the following topics: (a) experiences with severe behavior management in patients with ASD, including restraint implementation; (b)

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treatment differences across patients and departments; (c) relevant training received; (d)

relevant knowledge of ASD and behavioral function; and (e) perceived needs.

Chapter 2

Method

Recruitment

Research participants included two groups: medical trainees and early career physicians. Medical trainees included medical students, residents, and fellows who were currently in or had completed a rotation in the target departments of Emergency Medicine, Psychiatry, Pediatrics, and Neurology. Early career physicians (herein referred to as "physicians") included physicians in their first one-to-five years of post-supervised practice in the target departments. Participants were recruited from an urban hospital and affiliated medical school via direct emails sent by the author, through those in hospital leadership and administration roles (e.g., Dean, Student Affairs Officer, program director, chairs or heads of each of the target departments), and posted recruitment flyers.

The selected hospital is designated a Level 1 trauma hospital and uses trauma-informed care to guide treatment. In 2018, this hospital reported more than 28,000 hospital admissions and 3,000 trauma cases.

Procedures

Focus Groups with Medical Trainees

Three focus groups were conducted with a total of 22 medical trainees. Each focus group included six to eight participants, as guided by previous health research (Bender & Ewbank, 1994). Focus groups were conducted virtually via HIPAA-compliant video conferencing platform Cisco WebEx® v.40.11.4.15. Focus groups were conducted virtually to minimize potential health risks with in-person research at the time of data collection due to the COVID-19 pandemic and to increase the ease of communication

without necessary social distancing measures. Numerous advantages of virtual focus groups for both the researcher and participant are cited in the literature, including increased accessibility, decreased cost and use of resources, ease of recruitment for difficult-to-reach populations, the ability for all participants to see each other at one time, increased comfort for participants, and the wide range of available features and interactive tools (Stewart & Shamdasani, 2017; Turney & Pocknee, 2005; Tuttas, 2015).

All medical trainees participated in the focus group session for the entire duration, with the exception of one participant who had to leave the focus group early due to an unexpected emergency. This trainee participated in approximately 50% of the focus group session; their data were included in the qualitative data analysis.

The author of this paper and a bachelor's level cofacilitator led the virtual focus groups. Facilitator training involved comprehensively reviewing the focus group and interview guide, reviewing exemplars of de-identified focus group transcripts, meeting with the author for training and a question-and-answer session, and conducting a mock focus group session.

Participant consent forms were reviewed, signed, and returned to the facilitator in advance of the focus group. Prior to participation, the facilitator requested that each participant join from a private and confidential area to ensure data sensitivity. The facilitator and co-facilitator were each separately located in a private and confidential area. Participants were emailed an invitation to the locked WebEx meeting. Prior to being admitted by the facilitator, the participants waited in a virtual lobby area and were promptly admitted at the start of the focus group. The facilitator requested that participants remain unmuted with video cameras on during the focus group session to not

interrupt the flow of conversation. If there were technical issues such as audio overlapping, participants were asked by the co-facilitator to temporarily mute their audio. The comments feature was disabled to more closely resemble an in-person interaction and to promote active participation. Virtual focus groups were audio and video recorded by the facilitator at the start of the session.

Facilitators used a semi-structured guide to ask participants to describe their training and experiences with treating patients with ASD, severe behavior, implementation of restraint, and documentation of severe behavior and restraint, as well as their perceived needs with regard to patients with ASD. Open-ended questions were used to guide participants in describing their experiences; facilitators followed-up on topics that were not previously discussed or solicited responses from those participating less frequently. For example, the facilitator presented the guiding question, "Describe your experiences with patients with autism who engage in severe behavior in a hospital setting." At the start of each virtual session, facilitators requested that participants only describe experiences treating patients at the selected hospital. Responses from outside this institution were redirected and were omitted from data analysis. The mean duration of focus groups was 115.7 min (range, 109 to 119 min).

All relevant topics were discussed until the facilitator determined that the session had reached a point of saturation, wherein no new information or themes were being discussed. Participants were provided a $75 digital Amazon gift card after their participation. All study procedures were approved by the Rowan University Institutional Review Board. Patient confidentiality was maintained by storing recordings and de-identified data in a password-protected computer and were only accessed by the research

team. Participants are described by participant number with no identifiable participant information.

Interviews with Physicians

Three physician interviews were conducted. Procedures were identical to focus group methodology with the exception of conducting individual interviews rather than group participation. Individual interviews were conducted due to significant challenges scheduling a minimum of three physicians for a focus group session. Mean duration of interviews was 39 min (range, 36 to 41 min).

Autism Stigma and Knowledge Questionnaire

The Autism Stigma and Knowledge Questionnaire (ASK-Q; Harrison et al., 2017) was completed by all participants, with the exception of the one participant who did not complete the focus group. This 49-item survey presented statements about autism with response options of true, false, and don't know. We used the ASK-Q to measure participants' perceived knowledge of the core features of ASD and to better understand current medical training needs. We selected the ASK-Q for use with medical trainees and physicians due to its strong psychometric properties and cross-cultural utility as discussed by Harrison and colleagues (2019). The online questionnaire was administered using the Qualtrics® survey platform (2021) and responses were recorded anonymously. Participants were asked to complete the brief questionnaire without consulting resources. The questionnaire took a median of 3.5 min to complete (range, 2.4 to 18.1 min).

The ASK-Q yielded a total knowledge score and scores on the following subscales: (a) diagnosis, (b) etiology, (c) treatment, and (d) stigma. The questionnaire captured elements of the diagnostic criteria for ASD, as determined by the DSM-5 (APA,

2013), including (a) deficits in social communication and social interaction (e.g., "Children with autism cannot learn any social skills"; "Many children with autism have trouble understanding facial expressions"), and (b) restricted, repetitive behaviors, interests, or activities (e.g., "Many children with autism show the need for routines and sameness"; "Many children with autism repeatedly spin objects or flap their arms"; Harrison et al., 2017).

Data Analysis

Focus groups and interviews were audio and video recorded and transcribed at the group and participant level. Transcripts were thematically analyzed using the constant comparative method of qualitative data analysis (CCM; Glaser & Strauss, 1967; Strauss, 1987). The justification for using the CCM approach was to identify physician experiences and perceived needs, rather than provisional hypothesis testing. This method of data analysis allowed researchers to code data into explicit categories to establish theory and highlight salient themes that arose from participant input. This method is classified as a grounded-theory approach that is typically used to investigate novel empirical phenomena across fields such as psychology and health professions (Charmaz, 2008).

Participant transcripts were coded into categories that emerged from the analysis and were not limited; rather, data were coded into as many categories as applicable. Data were sorted into categories by comparing text to previous entries or introducing new categories. As categories emerged, operational definitions were created and revised. Subthemes were used in each category to accurately reflect theme content and facilitate consistent coding across the author and secondary coder. Data that could have been coded

in multiple categories were standardized by establishing specific rules and exclusionary criteria to promote interobserver agreement by independent data analysts. We followed the six phases of thematic analysis in psychology as described by Braun and Clarke (2006). These steps included: (1) becoming familiar with our data, (2) identifying initial codes of interesting ideas, (3) searching for themes, (4) reviewing themes, (5) defining themes, and (6) generating a scholarly report.

The first author trained a bachelor's level research assistant on independently coding data through reviewing sample transcripts and practice exercises until they reached two consecutive sessions with 100% coding accuracy. The second coder did not receive access to the video and audio recording. To determine interobserver agreement (IOA), 33% of each focus group and interview transcript was randomly selected and coded line-by-line by the independent coder. The first author calculated IOA by dividing the total line-by-line agreements by the total agreements plus disagreements and multiplying by 100. Disagreements were defined as differences in both commission (i.e., coding different categories for the same participant response) and omission (i.e., one coder coding a participant response and the other coder providing no code). Interobserver agreement was 91.7%. Disagreements were primarily categorized as omission (77.5%). Transcripts were analyzed after each focus group to allow for discussion of discrepancies and to clarify categories for future coding.

To quantify salience within and across participants, the total occurrences in each theme was summed for each participant and summed across participants (Morgan, 1997). Each example or rationale provided by participants was counted as one occurrence. A separate occurrence was documented once the participant provided a different rationale

or another participant responded. Revisiting a previous example or rationale was counted as a separate occurrence. Participant salience for each category was determined by dividing the frequency of occurrences in one theme by the total occurrences in all themes. For example, if Theme 1 was mentioned 11 times by the group and Theme 2 was mentioned 22 times, Theme 2 was regarded as a more salient theme at the group level. On the individual level, if one participant mentioned Theme 1 with only two occurrences out of only two coded themes (100%), while another participant mentioned Theme 2 five times out of 15 occurrences of coded themes (33.33%), Theme 1 was more salient to the first participant.

Autism Stigma and Knowledge Questionnaire

Responses on the ASK-Q are scored as correct or incorrect (Harrison et al., 2017). Correct participant responses resulted in one point. If a participant responded with "don't know", their answer was scored as incorrect. Participant responses across the four subscales were summed to determine a total score out of a maximum possible score of 48. Participant subscale responses were classified into adequate/inadequate knowledge for the diagnosis/symptoms, etiology, and treatment subscales and endorse/do not endorse for the stigma subscale. The following ranges demonstrate adequate knowledge of ASD: (a) diagnosis/symptoms, 11-18, (b) etiology, 11-16, and (c) treatment, 10-14. Stigma items were reverse scored as either endorsing stigma (range, 3-7) or endorsing minimal to no stigma (range, 0-2). All survey items on the stigma subscale were considered complex, meaning that these items were organized into the stigma subscale and one of the other knowledge subscales. For instance, if one participant endorsed stigma for the item, "Children with autism cannot learn any social skill", they would also

demonstrate low knowledge in the treatment subscale. Stigma scores did not load into the

total participant score as they were factored into one of the other knowledge scales.

Chapter 3

Results

Participant Demographics

The overall sample included 25 participants (i.e., 22 medical trainees, 3 physicians). A majority of participants were medical students (72%) and female (68%). The sample represented diverse races, including participants who were white (52%), Asian (20%), Hispanic (16%), and African American (12%). All of the target departments were represented with the largest percentage of our participants currently placed in or having completed a rotation within the following departments: Pediatrics (80%), Neurology (76%), Psychiatry (76%), and Emergency Medicine (72%). The other most frequently represented departments included Surgery (76%), Internal Medicine (76%), Family Medicine (72%), and Obstetrics/Gynecology (64%). Of note, participants may have endorsed multiple departments, particularly medical trainees whose training includes rotations across multiple disciplines. See Table A1 for a comprehensive breakdown of participants' gender, race, status, and current departments/rotations completed.

Focus Groups with Medical Trainees

Across the three medical trainee groups, 20 themes were identified. During focus group A, all 20 themes emerged. During focus groups B and C, no new themes emerged and 19 of 20 themes were coded in each group. See Table A2 for theme numbers and descriptions. See Table A3 for frequency and percentage of themes by participant status.

Salience by focus group is presented in Tables A4-6. The mean rank order correlation between each focus group and the overall focus group rankings was 0.68

(range, 0.56 to 0.85) representing a strong positive correlation. The top five most salient themes will be described first, in order of salience at the focus group level. Remaining themes are grouped by categories for ease of interpretation. The five most frequently endorsed themes were:

1. Trainees are not responsible for managing severe behavior and implementing restraint, and were thus unfamiliar with comprehensive restraint protocols.

2. Trainees described or suggested alternative strategies used by themselves or others for treating patients with ASD and severe behavior.

3. Trainees discussed negative reactions or perceptions of restraint by themselves, physicians, caregivers, and patients.

4. Trainees reported the helpful role of accompanying caregivers during patient appointments in the treatment of patients with ASD and severe behavior.

5. Trainees indicated limited practical experience treating patients with ASD and that experiences may vary by hospital department.

Restraint Implementation and Protocols (Theme 1)

The most salient theme reported by medical trainees related to the responsibility falling on others to manage patient severe behavior and implement restraint. Medical trainees reported that because other hospital professionals were responsible for implementing restraint, they were not consistently able to report comprehensive restraint protocols related to implementation and documentation. Subthemes included: (a) consulting other hospital professionals and/or departments for the management of severe

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behavior (i.e., nurses, rapid response teams, security, psychiatry, child life, behavioral medicine); (b) removing themselves from the situation, (c) observing protocols implemented by others (e.g., physicians ordering restraint) and/or limited to no experience carrying out protocols themselves; and (d) reporting that protocol knowledge and responsibility may vary by status (e.g., resident vs. medical student) and department (e.g., increased responsibility of psychiatry in restraint protocols). For example:

P11: So I'm currently on psychiatry right now, and we have a procedure called BRRT, I think it's like behavior rapid response team, I think it's what it stands for, but it is for when a patient's behavior is escalated, and either dangerous to themselves or others, psychiatrists are called. And there's a lot of like, steps to the protocol about when it happens that I don't remember them, but I know that that is a protocol we have in place, and I'm not sure how often it's used with patients with autism.

P15: I think it's really important to bring other people into the room like a nurse at least, to try to deescalate things.

P9: I'm going to speak from my own familiarity is having the security staff nearby and nurses nearby and technicians who are very brave people and can be there ready to assist.

P1: It's usually the team so like the nurses would probably are usually the ones to suggest it and then I believe that the physicians have to put in the order for it.

P10: I think we use the term threat to themselves pretty loosely, whereas like a person, I think the protocol in [state] for restraints is a physician can place the order for the restraint and then they have to evaluate them and then it's on like a two-hour basis, they have to sort of reevaluate, are they still a threat to themselves.

Alternative Strategies to Treat Patients with ASD and Severe Behavior (Theme 2)

The second most salient theme reported by medical trainees was the identification

of various alternative strategies for managing severe behavior in patients with ASD.

Medical trainees reported strategies they have used personally or have observed used by

others, and also proposed strategies they would use when asked to describe their response

to patients with ASD engaging in severe behavior. Subthemes included: (a) adapting the

physical environment (e.g., moving patient to a different physical location, reducing

noise and distraction, reducing number of professionals present during appointment); (b)

changing their medical approach (e.g., calmer/quieter tone, altering or forgoing medical

assessments, conducting a more comprehensive physical examination to avoid undetected

medical issues, attempting to involve the patient, simple explanations and repetition); (c)

using alternative equipment, if available (e.g., helmet, pillow); (d) providing access to

attention or tangible items (e.g., active play, access to stethoscope) and reduced demands

(e.g., allowing the patient to engage in special interests and/or repetitive behaviors that

may otherwise interfere with medical examinations, breaks); and (e) encouraging

appropriate behavior and discussing reinforcers with the patient. For example:

P18: So it was known that if someone had autism, more of the games were located

in one room. So oftentimes it was known that they'd go there.

P4: I would probably give them their physical space. I had a patient previously

that I feel like the closer you got to them for a physical exam or just talk to them, the

more nervous or agitated they get. So just stepping back, going to maybe the corner of the

room.

P11: I try to always be very clear and communicative with my patients. But I think with patients who have autism, I try to really make sure that communication comes through with little nuance, like not as much nuance or not as much reading between the lines, but more explicit.

P13: I also try to be really careful to keep things like as low stimulation as possible, so bringing my voice down, not being any louder than necessary. If I need my patient to look up, making sure that I'm not asking them to look up into bright lights, things like that.

P1: I remember being on pedes outpatient rotation I had a little girl and she was on the autism spectrum disorder and she was really fixated on my stethoscope, so while I was examining her, I just let her just play with my stethoscope and it just made things a lot more easier.

P22: And that I think was handled very well by the resident, because they did all the things that she said, made sure that the patient got a room away from a lot of the noise. So I noticed the room, I mean, in our emergency room, there are rooms that are closer to the entrance, and then there are rooms further away, like in the corner. So making sure that the patient was in a quieter area.

P18: I think the other thing that I saw from a practitioner's point of view, not what I did personally, was when the physician would talk to the patient, they'd kind of talk about what are things that the child with autism would want to do after the appointment. And really catering that to, you know, if they like ice cream, I remember there's one patient where he really liked french fries. So I think there was just more focus in a patient with autism.

Negative Reactions and Perceptions of Restraint Implementation (Theme 3)

The third most salient medical trainee theme included negative reactions/assessments of restraint by trainees themselves, physicians, caregivers, and patients alike. Subthemes included: (a) observing patient expressions of pain or resistance to restraint, (b) observing patient disinterest in further medical care post-restraint, (c) observing caregivers having sad or ambivalent reactions to restraint, (d) avoiding reporting restraint use to caregivers, (e) having the desire to remove restraint, (f) perceiving restraint as restricting patient's rights or treating a patient as nonhuman, (g) perceiving the use of restraint as a last resort, and (h) reporting observations of restraint implementation as uncomfortable. For example:

P15: I think her grandmother was with us and her reaction was both like she was very sad, but at the same time she knew it was the right thing.

P18: My experience involved a caregiver physically hugging the patient and the child to prevent their arms from then reaching their back. The child, we weren't really able to deescalate him like emotionally while he was going through the physical restraint, and he kept on saying like, 'Why are you hurting me?' So it just kind of seemed like until the parent stopped hugging him, it was this idea of like we're causing harm to him, and nothing that we could say to explain it could help him understand.

P9: So now we had to move him and treat him like an animal.

P9: I just remember, like the scared intern watching patients get put down and it was like, horrifying.

P7: The last thing we want to do is put someone down into four-point restraint against their will.

P10: But personally, I've seen restraints been [*sic*] used not on autistic patients in the hospital, but used I think improperly in the hospital. I think we use the term threat to themselves pretty loosely.

P7: I think depending on the staff member and if the patient is like looking for some insight as to why like the restraint might have been used, I think that conversation may happen, but I think it really just it's so dependent on the case itself, like, if the patient's very open to the conversation I think the staff will be more than willing to have that conversation, but sometimes we found that it could just further agitate the patient so we may just avoid it, let them out of restraint and just let them go because they want nothing with us at that point.

P17: If typically, they resisted in the beginning, and then – well, actually, you know what, they prob – they resist throughout the entire thing. But the initial disruption I think is a high level of resistance, and then over time they understand that you're not hurting them, and they can calm down a little bit. But if I'm trying to compare a patient with autism on restraints to a normal patient, I would say they're always at a heightened level, and they're never going to get down to a very calm level until you release the restraint.

P7: We personally don't ever really try to tell family if it's possible, just because I think that can be really upsetting to family members, but if it has to do with their care or if they're inquiring specifically about why they're not being let out of the hospital then that's kind of the supporting evidence that we would have to like share it with them to let them know why.

Helpful Role of Caregivers During Appointments for Patients with ASD (Theme 4)

Medical trainees also reported the helpful role of the patients' accompanying caregivers during appointments for managing severe behavior. Subthemes included caregivers: (a) providing a model of how to best interact with the patient for the medical trainee to follow, (b) assisting with communication and triggers to severe behavior, (c) implementing restraint rather than other hospital professionals, (d) distracting patients, and (e) providing a sense of comfort. For example:

P4: A lot of my experiences with autistic patients were in pediatric outpatient settings, so I saw a greater role of parents over here in these scenarios where they did most of the talking and most of the interacting.

P10: I think how I approached that visit was sort of letting the mom do a lot of the talking and sort of getting a good understanding of how the mom addresses the care of that child, and sort of letting her feel like she was sort of in control because it was a sort of chaotic situation.

P9: But I find when I'm dealing with pediatric patients in particular, I tend to follow suit with the parent or the caregiver, because they know more about that child than I do, they are with them on the regular, they understand their communication a little bit better, and so I try to mimic or shadow what mom is doing, or dad is doing to kind of leverage the child to participate in the exam or interview.

P18: I think for younger children, the child would often sit in the parent's lap. For someone who was 12, I think the parent would be nearby, but not often in the parent's lap.

P21: Instead of using the papoose, we let the mom hold, which we kind of typically don't do, just because it's like a lot easier to just papoose them, you can place the sutures or remove them. But instead, you know, having the mom kind of be the restraint there so that we could remove the staples.

Limited Practical ASD Experience and Experience Varying by Department (Theme 5)

Medical trainees expressed generally limited experience treating patients with ASD. They also indicated that experience may vary by hospital department, and thus, departments that serve more individuals with ASD are perceived to have more successful patient interactions and subsequent treatment of patients with ASD. Subthemes included: (a) reporting different experiences by department and target population served (e.g., neurology and pediatrics treating more patients with ASD); (b) perceiving specific departments as having more successful physician-patient interactions for patients with ASD; and (c) perceiving the treatment of unrelated concerns in patients with ASD as not building their competency in the treatment of patients with ASD. Examples included:

P3: I think I've only seen like four or five patients with autism over the past year in the clinical world.

P9: And for some patients who get that aggressive sometimes that there's a committee, at least in our department, where we review, it's multidisciplinary committee with like an ED behavioral psychologist, the medical director and a nursing and things like that, that kind of come together to try to develop the best way, like how can we approach this patient as soon as they hit the door.

P11: The patient had autism, and he was there for his regular checkup so my experiences have been limited but I think like I've seen bits and pieces.

P20: I've probably only taken care of a handful of patients in ED with autism.

P21: I haven't seen a lot of patients with autism. I saw a few as a student on my peds rotation, and typically they were presenting more so in like clinics or well visits. And so it wasn't really something that was being necessarily addressed at the time.

P21: But other departments where you encounter patients say pediatrics for example more frequently. Or neurology, or wherever there may be other comorbidities where you see autism. Those interactions were handled better.

The remaining 15 themes are grouped into relevant categories for ease of discussion and presented below.

Training, Knowledge, and Treatment Specific to ASD

Lack of Formal ASD Training (Theme 7)

Medical trainees identified a lack of formal training related to treating patients with ASD. Participants indicated that their early training in medical school included a few lectures and/or didactics about the core features of ASD, and identified this as a gap in their curriculum. Participants also expressed a lack of formal training and that the training received was delivered by professionals without specific expertise in ASD. Subthemes of this category included: (a) having a few lectures about features of ASD, but limited training in practical knowledge and best treatment for this patient population; (b) indicating that most of their knowledge gained has been through direct patient experiences; (c) expressing that knowledge gained has resulted from mentors; (d) discussing prior experiences outside of their medical training; and (e) pursuing knowledge on their own from sources outside their medical training, such as the

American Psychological Association and Autistic Self Advocacy Network, UpToDate

(2021), and brief literature reviews and/or other scholarly publications. For example:

P7: For me, like since I've gone through almost like three years of residency now,

I feel like, yeah, it's unfortunate. I feel like there's not more formal training specifically

for ASD. For me personally, like the first two years didactic trainings, like we would get

lectures on them, like lectures on the topic, and then very rarely would we have someone

who is very, like specialized in that disorder and be able to talk to us specifically about

management techniques and things. And then besides that, it would just be like coming

across patients and like issues that you may have had or things that you wish you had

done better than going to like some sort of like mentor and being able to like say, like,

hey, like what, you know, like, can I get some tips here, some pointers, so besides that,

yeah, I wish that there was more formal training, but there's not, at least not, there wasn't

for me.

P9: That's something I've been taught to do by my faculty, but again nothing

formal.

P11: I have some experience volunteer work that I did with children with autism,

but it's still very different in a medical setting.

P12: I think that we had some like didactic maybe during like the end of our

second year during like a psychiatry block. And then I had a little bit of exposure during a

pediatric neurology block, but even that was limited more to diagnosis than treatment, so

I don't think that in my medical school training, I've really ever received any training or

formal education on the treatment of autism in terms of like the disease progression. And

I think that that's like a huge miss now that we're talking about it, and honestly, I hadn't reflected about it.

Perceived Knowledge of ASD (Theme 20)

Although their experience with patients with ASD and severe behavior was limited, medical trainees described knowledge of the core features of ASD and/or having observed the presenting features during their limited interactions with patients with ASD. Subthemes included perceived: (a) sensory sensitivities, (b) communication differences, (c) fixations/restricted interests, and (d) differences in severity of ASD. For example:

P9: So that kind of communication with the child or adult with autism or significant developmental delay can be a little difficult.

P3: The presenting symptoms with fixation on like, objects, and she, like would often complain that, you know, different types of fabrics and shirts and sheets and things would feel very strange to her, and it was like very specifically what her mom and dad could have her wear and started causing issues in school with her paying attention to sounds that were going on outside or, like, if the air in the room was coming out of the vent a weird way like she would become fixated on that.

P2: I think … the communication is the big difference when you're dealing with a patient with autism or on an autism spectrum disorder versus a patient that can't communicate very well.

Negative Perceptions of ASD Prevalent Within Medical Culture (Theme 19)

Medical trainees expressed negative perceptions about treating patients with ASD they may personally hold or have observed by other medical professionals. Subthemes of negative perceptions included: (a) discussing negative perceptions and assumptions

regarding the treatment of patients with ASD (e.g., scary, bad); and (b) viewing patients with ASD as more challenging or difficult to treat. For example:

P15: I guess like our subconscious kind of creeping in or like our like initial kind of thoughts on those with autism and how we kind of approach them or like our biases on that.

P9: I don't know if it's my own bias that I'm like, "Oh, this person or child has autism, I must treat them differently." And so I feel like that unconscious or subconscious bias comes in a little bit.

P13: And that's been like, a little bit uncomfortable, in part because I feel like I've had a lot of people who turn towards to be like, "Oh, this person has developmental disabilities, or this person has autism, like, oh, are they upset and like "Are they upset?" is always the first question, it's sort of like assuming that it's going to be a negative, scary bad interaction when it's usually been pretty okay.

P9: And so navigating that is difficult, because there's like, I was trying to say before, you don't want to treat them like they're different patients, but sometimes you have to, and where that line is, can be very tough to identify.

Severe Behavior in Patients with ASD

Higher Tolerance for Severe Behavior in Patients with ASD (Theme 13)

Medical trainees reported higher tolerance for severe behavior in patients with ASD, expressing that their response for patients with an ASD diagnosis who are engaging in severe behavior may be different compared to their response to others without an ASD diagnosis. Subthemes included: (a) describing severe behavior as more complex for

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patients with ASD and (b) observing fewer restraints with patients with ASD. Examples included:

P7: Obviously it's not as simple as like maybe another patient who's getting aggressive.

P20: And I think most staff are more likely to just be more willing to take the time with someone when they know that this is a behavioral issue that's been diagnosed.

P7: I just wanted to say like, because it made me think of a patient, like you had mentioned before, if like, there are different, like approaches or techniques, or is that threshold a little bit different for those with like cognitive difficulties, I think, like, in terms of the staff, and I mean, I could be wrong, but and it could be my own bias, but I think for those with cognitive difficulties or with a history of ASD, I think there is, like, maybe a little bit more of an effort on the staff's part to try to redirect so that restraints are not necessary.

P17: I think it comes down to the history of the patient, the intent of the patient, and if the staff or the patient is at harm. So if we know a patient has been diagnosed with autism and they're undergoing treatment, or it's a known thing, then us, we can – as physicians, we can incorporate that into how we react and how we respond in terms of escalation of restraint, whether it's medication or physical restraint. And then, the intent, patients with autism, they're – I don't think that their intent is really to harm other people.

Internal Causes of Severe Behavior (Theme 6)

Medical trainees identified internal characteristics or traits as the reason why severe behavior may occur in patients with ASD. Internal subthemes included: (a) inability to communicate, (b) loss of control, (c) pain, (d) coping mechanism and/or self-

regulation, (e) anger or feeling misunderstood, (f) sensory stimulation/overload, (g) maintaining "inner peace" and comfort, and (h) low frustration tolerance. For example:

P8: I think that there's something they want, or there's something that they need, that they're not getting to put it really simply, there's something that is triggering them, something doesn't feel right, but maybe they can't say what it is. So I think something feels off to them, they don't feel comfortable.

P5: It can be that they're having aggressive behaviors because they're in pain and just like trying to figure that out.

P7: Maybe it's a coping mechanism, just a form for them to cope.

P5: I think they also tend to sometimes have like a low frustration tolerance and so even if the patient can communicate, they might get frustrated and act out more easily than someone who doesn't have autism.

P17: I think it's just this – like everyone's been saying, it's an acting out because their environment has been disrupted, and their own inner peace has been completely just put off course for a little bit. And so they're acting out to try to – because that's the only way they know how.

P22: I think just the idea of having a stranger poke and prod and touch you can be overwhelming and instigate fear in and of itself. Normal – like we – I wouldn't want it, so I can't imagine how scary or overwhelming it might be for the patient. And I think it's a very much of a reactive process that if someone touches you, you hit them. I mean, that's the way – it's just very reactive without even thinking about it. It's not that they have any intention to hurt anyone, but that's – in what they can do and their capacity, that's how they react.

External Causes of Severe Behavior (Theme 16)

Medical trainees also expressed that severe behavior may be caused by external factors related to the environment and the role of others outside of the patients themselves. Subthemes included: (a) hospital environment as loud, scary, and/or intimidating; (b) physician responsibility to manage the environment; (c) patient learned behavior; (d) history of reinforcement; and (d) failed intervention. Examples included:

P13: I was actually going to say something similar, like the hospital or even the clinic can be just a really distressing environment for anyone.

P1: I would also define severe behavior as one in which different modes of like intervention has failed. So whether it be like from medication or whether it be from just like different behavior modification type of interventions, if those things are failed, and I probably characterize it as severe behavior.

P5: They might find that like the behavior gets them something that they desire like it has a positive reward for them.

P9: I always feel a little self conscious about, I don't want to trigger the patient, I don't want to create an uncontrollable like, emotional outburst.

Negative Description of Severe Behavior (Theme 11)

Medical trainees expressed a negative perception and/or evaluation of severe behavior in medical settings. Subthemes included mention of severe behavior as: (a) violent, (b) aggressive, (c) threatening, (d) harmful to oneself or others, (e) not redirectable, (f) disproportionate reaction to a given stimulus, and (g) impeding medical professional's ability to deliver medical care. Examples included:

P20: I don't really have like great words, like ways to put this into words, but like patients who have like certain behaviors that are kind of like potentially violent or aggressive, or like you know patients who fight or might hit.

P21: I would describe severe behavior as anything that's like, you know, self-destructive or harmful to self, or harmful to other people, they're interacting. Or anything that's like kind of impeding with like you providing care for them, any like behavior that's preventing you from being able to do that, in a way that's like harmful, either to the patient or for another person.

P9: One thing that kept creeping back in my head was a response that's disproportionate to the stimulus.

P3: So anytime I think of severe behavior, I would say it's anything that poses an immediate threat to the individual themselves or to anybody around them. So for example, self-harm or any acts or actions that could lead to self-harm of either the individual or somebody else. So for instance, it could be like, disregards for personal safety, like running into the middle of the street or not thinking about consequences that can have severe thinking about actions that can have severe consequences.

Differentiation Between Different Types of Severe Behavior (Theme 17)

Medical trainees distinguished between several types of severe and/or challenging behavior and described differences between terms used to describe these behaviors (e.g., severe behavior, challenging behavior, repetitive behavior, crisis). Subthemes include: (a) self-injurious behavior vs. other behavior, (b) repetitive behavior vs. severe behavior, and (c) crisis vs. severe behavior. Examples included:

P6: A like a lot of the patients have self-injurious behaviors, but it might just be like skin picking, or like something like that, which I wouldn't necessarily call like a severe behavior, I would say like something that is going to cause like serious injury, or like even death to themselves or someone else.

P13: I feel like I have a hard time drawing a line across, like what I would specifically always classify as severe once you get beyond things where the patient is doing harm to themselves where I'm worried about like physical injury occurring.

P10: I think the word crisis has a time element to it versus severe behavior could just be sort of like a descriptive term, or like a noun with an adjective sort of added to it, that doesn't have to be as time sensitive.

P10: But then also in this one adult, he was fixated on his bowel movements, I don't know if this would be severe, but he was using suppositories almost every day, because he would fixate on not having gone to the bathroom for like, like his sort of like the window for him to go to the bathroom was like every two to three hours. So something like that I would consider severe.

Restraint Implementation Across Hospital Patients

Algorithms and Decision-Making Processes to Restraint and Response (Theme 14)

Medical trainees reported a decision-making approach to deciding whether to respond to severe behavior and implement restraint. Medical trainees indicated having an algorithm or step-wise progression when deciding whether restraint implementation was warranted and described differential responses to different types of severe behavior. Subthemes included: (a) differentiating between offensive vs. defensive approaches, (b) ensuring personal safety vs. patient safety, (c) implementing restraint quicker for medical

or physical concerns due to self-injurious behavior vs. aggression, (d) implementing

restraint quicker for physical aggression vs. verbal aggression, and (e) using an algorithm

to inform severe behavior management and type of restraint used (e.g., verbal de-

escalation, then chemical restraint, followed by physical restraint). For example:

P7: Before physical restraints, a lot of times we do try to use chemical ones.

P12: I think [participant name] really laid out like a really like methodical way to

go through like, how you would kind of like, starting with verbal de-escalation all the

way up to restraints or some sort of chemical response.

P14: I would kind of think that, like the urgency would be the same, but instead of

like -- or like trying to, I guess you're worried less about your own safety, much less

about your own safety and way more about their safety. So like, the focus, I guess, is

different, so like, you obviously want to intervene quickly, but I feel like this is more like

offensive than defensive, because you're going to be fine, you need to make sure that

they're not going to like give themselves a concussion or something.

P21: But if it was just like aggressive, like verbal behavior, or some other like

milder form of aggressions, then I would certainly like not necessarily jump to physical

or chemical restraint if I could try to deescalate the situation in other ways. But if I were

in, you know, harm's way, then I would move towards more physical restraint or if it – if

the situation required chemical restraint.

Medication as a Proactive Strategy to Manage Severe Behavior for Patients with ASD

(Theme 18)

Medical trainees expressed using medication as a proactive strategy for treating

patients with ASD. Subthemes included: (a) prescribing medication for medical

procedures, and (b) administering medication during the appointment to limit behaviors that are perceived to interfere with the medical appointment. Examples included:

P3: The difficulty was trying to figure out what's the best medication you can prescribe in this case to kind of limit those issues pertaining to tactile and auditory overload.

P20: And typically, you know, we can like do any extreme from like just pain meds or like a little bit of medication to calm someone down for that procedure, to like full-on sedation, having the patient asleep for the procedure. And, you know, I think because of his known behavior, and, you know, not wanting to risk, you know, him biting or getting worked up, and for his comfort, we opted to do like a full sedation for the procedure.

Observable Patient Characteristics as a Predictor of Restraint Across Hospital Patients (Theme 8)

Certain specific patient characteristics that are easily observed were identified as a predictor to restraint implementation across hospital patients. Subthemes included: (a) age; (b) race; (c) gender; (d) size, height, or weight; (e) non-compliance; (f) perception of threatening behavior or non-compliance at the time of presentation; and (g) suicidality or homicidality. Examples included:

P21: But certainly, I'd be more included to restrain someone older because I would think that they're – it could escalate to a point that's more dangerous than a – like child.

P9: I definitely see males in restraints more.

P7: Just being like a bigger younger person sometimes can kind of make you like be more likely to be like, just interpreted as threatening, and then you in those kinds of situations where you [sic] being put into restraint.

P10: It [restraint] makes a lot of sense; someone's in the emergency department acutely agitated and is like an imminent threat to themselves or someone else.

P7: I would see those with a history of autism coming in for aggression or something else, suicidality, homicidally [*sic*] so they're oftentimes we would have to restrain them chemically or physically.

External Characteristics as a Predictor of Restraint Across Hospital Patients (Theme 9)

External characteristics were identified by medical trainees as predictors to restraint. This theme includes statements related to the patient's environment and background that are not readily observable (e.g., criminal status), and factors not related to the patient (e.g., hospital environment). Subthemes included: (a) diagnosis or features of a diagnosis, (b) limited communication abilities or a language barrier, (c) cognitive ability, (d) criminal status, (e) geographic location, (f) time of day, and (g) limited accessibility to alternatives within the department. For example:

P10: I think that possibly the time of day also, because of sun downing, and stuff like that a lot of restraints are used for patients with delirium versus dementia, and they'll get aggressive towards the end of the day, you can see patients in restraints then.

P9: Where the patient is in the hospital, or where they are in their treatment setting might also like we are much more likely to put somebody in restraints in a chaotic emergency department than perhaps somebody on the floor. So I just think that where

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that you are in the hospital, because of your resources available might make a patient more likely to be restrained or not.

P12: I feel like if it was a patient coming off the street and especially like being in [city], there are so many different stereotypes about like drug seeking behaviors and things like that, that kind of jump to other conclusions.

P21: I don't know like … what resources we have in the ED, other than physical and chemical restraints.

P20: But I think sometimes we don't always have that time. So if we know that that's not the case, I think we're more likely to kind of do what we need to do to get things done quicker.

P20: But if you can't communicate with them … I think you err more on the side of caution.

Limitations to Treatment

Limitations and Areas for Improvement in Service Delivery for Patients with ASD and Severe Behavior (Theme 10)

Medical trainees identified limitations of current institutional policies and systems that affect their service delivery for patients with ASD who engage in severe behavior. Subthemes included: (a) lack of time to complete a thorough chart review; (b) suggested training opportunities that would benefit patient care (e.g., formal ASD training, applied behavior analysis training, incorporation of simulated patients with ASD, restraint and severe behavior management training, communication and de-escalation techniques); and (c) identified need for unified protocols to manage severe behavior. For example:

P18: That's kind of how I get my information if I have the time to… do a chart, thorough chart review.

P21: For me personally, I think just training. But having a formal training on what even is severe behavior, how is that defined? What tactics, you know, what can you do when dealing with these patients.

P19: So maybe kind of like a simulated patient situation with patients with autism would be like a good training to do.

P18: And having like a protocol. I realize that sometimes you're in the moment and you forget maybe what you're supposed to do. So kind of whether it's something that can be included within EPIC, or if it's posted up, just because I think we like algorithms to follow.

P20: Especially the department specific, and going through like these are the resources we have in this department, And like X, Y, and Z scenarios, these are the next steps that you would do, would be really helpful. Yeah I think basically just training and education.

P9: I would have liked to have had more specific training and being able to communicate effectively, both with patients and families when trying to provide medical care.

Inconsistencies of and Limitations to the Documentation System that Inhibit Service Delivery (Theme 15)

Medical trainees also expressed inconsistent documentation of severe behavior and current diagnoses in the electronic medical health system. Subthemes included: (a) inconsistent pop-up and/or flagging system to alert severe behavior, (b) lack of

comprehensive patient information and/or background, (c) limited documentation accessibility across external healthcare systems, and (d) current diagnoses not accurately reflected in presenting concerns section of the patient electronic record. Examples included:

P1: So sometimes it'll be written, like, if you look at, like a previous note from the patient, it might be in their history of presenting illness, it might be there, or sometimes like, for example, I remember being, when I did my emergency medicine rotation, the patients are first seen in triage, so it may be also noted in their triage note.

P5: It's not like a specific red flag that says like the patient has been agitated before, it's more of just like something that you might figure out through digging, at least in my experience.

P3: A lot of times, I mean, there's an option for what's called care everywhere in the electronic medical record system that we use, but it's usually a very limited subset of hospitals … and there's a lot of different electronic medical system out there, yeah, no matter not even have been documented at a previous hospital either.

P7: For us personally, like I think it's more so like a note, just like any other sort of progress note. There's no flag and there's no like way to filter out I think even for like a restraint note itself, you would have to pretty much just kind of flip through all the different notes to see if there happens to be one for a behavioral rapid response or something like that.

P9: Some of them do have the pop ups, not that they're pop ups, but some of them do have a symbol next to their name, but sometimes, if that hasn't been, I would say that that documentation is pretty inconsistent, but we're getting better with it, but otherwise,

you just kind of look through the chart and see that they've been here or to surrounding hospitals 5, 6, 7 times in the last month or within the last year.

Lack of Crisis Training and Crisis-Related Knowledge (Theme 12)

Medical trainees expressed a lack of foundational knowledge, training, and experience regarding crisis. Subthemes included: (a) lack of knowledge specific to crisis situations and protocols, (b) lack of formal crisis training and management, and (c) crisis knowledge and training varying by department and/or specialty. For example:

P1: I don't think I ever fully, sometimes when I remember being on my psychiatry rotation and hearing, oh, we have to crisis this person, I don't think I even fully understood what was meant by that, or what goes into that, but I'm just gonna take a guess and say that, um, it's someone who's in maybe, like, a severe, just having like an acute episode of some type of psychiatric condition. For example, maybe like, suicidal, someone who attempted suicide.

P5: Crisis is more a term used in psychiatry because it's … for like involuntary commitment and things like that.

P7: I got absolutely none in medical school, even though I think that really would have been important. And then even in residency training, I feel like it's limited. I think in the past, they've tried to do more like hands on, like teaching and have people who are like, specialized in this kind of thing, come and talk to us, but it's not a consistent thing.

P2: I don't think we get that training as medical students. I think the training comes more in your residency.

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Interviews with Physicians

During the three physician interviews, no new themes emerged. All 20 themes identified during medical trainee focus groups were discussed by physicians. Four of the top five most salient themes from the medical trainee participants were also ranked within the top five for the physician participants. The medical trainees' Theme 7 (i.e., observable patient characteristics as a predictor of restraint) was ranked first in salience in the physician interviews, whereas, Theme 5 was ranked 6 in salience from physician interviews. The mean rank order correlation between each interview and the overall interview ranking was 0.69 (range, 0.46 to 0.86), representing a strong positive correlation. The mean rank order correlation between focus groups and interviews was 0.71, representing a strong positive correlation. Frequency and percentage of themes by participant status and by individual participant are presented in Tables 3 and 7, respectively.

Autism Stigma and Knowledge Questionnaire

Survey responses were collected from 24 of 25 participants. The medical trainee that was unable to participate in the full focus group session due to an emergency did not complete the survey. See Figure A1 for a graphical representation of aggregated ASK-Q individual scores and means across the medical trainee focus groups and physician interviews. See Table A7 for ASK-Q means and percentage of participants with adequate scores by participant status.

Medical trainees demonstrated a mean score of 15.2 out of 18 ($SD = 1.4$) in the diagnosis/symptoms subscale, 12.4 out of 16 ($SD = 2.2$; range, 12 to 18) in the etiology subscale, 12.3 out of 14 ($SD = 1.4$; range, 7 to 15) in the treatment subscale, 0.9 out of 7

($SD = 1.0$; range 0 to 3) in the stigma subscale, and 39.9 out of 48 ($SD = 3.8$; range, 30 to 45) in the total score. Of the medical trainees, 100% demonstrated adequate scores in the diagnosis/symptoms subscale, 80.9% in the etiology subscale, 90.4% in the treatment subscale, 90.4% in the stigma subscale, and 95.5% in the total score.

Physicians demonstrated a mean score of 15 out of 18 ($SD = 2$; range, 13 to 17) in the diagnosis/symptoms subscale, 14.7 out of 16 ($SD = 0.6$; range, 14 to 15) in the etiology subscale, 13.3 out of 14 ($SD = 1.2$; range, 12 to 14) in the treatment subscale, 0.3 out of 7 ($SD = 0.6$; range 0 to 1) in the stigma subscale, and 43 out of 48 ($SD = 1$; range 42 to 44) in the total score. Physicians demonstrated 100% adequate total and subscale scores.

Chapter 4

Discussion

This study provides important information regarding physicians' experience treating patients with ASD and severe behavior, and restraint implementation. The aim of this exploratory research was to gather qualitative information about how physicians manage severe behavior in patients with ASD and variables that may affect physician decision-making in restraint implementation. The existing restraint literature has largely focused on general patient populations (e.g., Grimes et al., 2012; Larue et al., 2009) or examined restraint use within specific departments, especially psychiatry and emergency departments (e.g., Delaney et al., 2005; Wong et al., 2019; Wong et al., 2020). Although some studies have focused on neurodiverse populations (e.g., Friedman & Crabb, 2018) or more specifically the ASD population, these investigations are often limited to pediatric populations (e.g., Johnson & Rodriquez, 2013; O'Donoghue et al., 2020). The current investigation specifically focused on patients with ASD and also included participants from a range of target departments to more accurately represent physician experiences with the treatment of patients with ASD across the lifespan. The current study also extends the literature by focusing on medical trainees and early-career physicians as opposed to a wide variety of healthcare providers (i.e. physicians, psychologists, care managers) included in previous studies (Zerbo et al., 2015). This study also extends the literature on areas for improvement in healthcare for patients with ASD (e.g., Zerbo et al., 2015), to focus specifically on perceived needs in treating severe behavior in this patient population.

The purpose of the thematic analysis was to identify salient themes across participants. Although there was potential for differing themes to emerge across medical trainees and early career physicians due to differences in experiences and responsibilities, our findings did not suggest differences between medical trainees and physicians in their experiences with and perspectives on severe behavior in patients with ASD. No new themes emerged from the physician interviews which poses an even stronger argument for the need for an increase in education related to ASD and severe behavior management during medical training and early career practice and institutional policies to improve service delivery to this patient population. Although our data were collected at one urban teaching hospital, it is a direct representation of other hospital systems nation-wide. The inclusion of certain target departments (e.g., Emergency Department) and the wide array of patients served at this particular hospital were strategically selected to resemble other hospital systems across the nation.

One of the most salient themes described by participants was that they consulted other hospital professionals to manage severe behavior, assist in a crisis situation, and implement restraint. As a result, participants were unfamiliar with comprehensive restraint protocols and did not have ample experience where restraint was implemented by them personally. These results are supported by a systematic literature review conducted by Choi et al. (2019) in which rapid response teams are commonly used in medical settings to assist with acute medical crises and have more recently been adapted to manage psychiatric crises. Behavioral rapid response teams are led by a nurse and security guard at minimum, and do not often involve physicians. Once the team is alerted, medical trainees and physicians can then attend to other patients while others manage the

severe behavior. This approach explains why medical trainees and physicians alike were not able to report knowledge of comprehensive restraint protocols. This point was further supported by a response from one medical trainee who reported receiving guidance from an attending physician to continue treating other patients while the severe behavior was managed by the rapid response team.

The use of rapid response teams is not unique to the hospital included in the current study (e.g., Choi et al., 2019). Although studies demonstrate that these teams are effective for improved medical outcomes for the general patient population (e.g., cardiac arrest) and behavioral outcomes for patients with psychiatric crisis (e.g., reduced restraint use), this team's feasibility for patients with ASD and severe behavior has not been explored in the literature. Given the demands placed on physicians and the wide range of clients treated, reliance on such specialized trained teams may be an effective means to assist with managing severe behavior in patients with ASD. Overall, this study demonstrates the need for specialized training in severe behavior and ASD for physicians and specialized teams alike, in addition to the safest and least-restrictive management of severe behavior within hospital patients with ASD. As evidenced by our qualitative data, participants identified a gap in knowledge specific to behavioral function and practical skills to treat neurodiverse patients. In addition to emphasizing the need for the addition of ASD-specific skills and severe behavior management strategies in the medical curriculum, future research should explore the competencies and ASD-specific training of rapid response team members.

Another salient theme identified by participants was the wide range of alternative strategies to treat patients with ASD and severe behavior, ranging from the use of

caregivers to adaptations to a physician's medical approach or the physical environment. The helpful role of caregivers in ASD-related medical care has been established in the literature (e.g., Morris et al., 2019; Zerbo et al., 2015; Zwaigenbaum et al. 2016). Although caregivers can assist by providing detailed explanations of a patient's triggers and assist with overall communication, there are limitations to relying exclusively on those accompanying a patient to a medical appointment. Participants recognized that collaborating with caregivers is a part of their role, but noted that appointments including patients with ASD and their caregivers take considerably more time (Zerbo et al., 2015). Another limitation includes challenges to healthcare independence for patients with ASD. Caregivers serve a critical role for children and adolescents with ASD; however, the push for independent healthcare access is evident in the literature (e.g., Cheak-Zamora et al., 2017). Healthcare transition services are intended to prepare adolescents with special healthcare needs for an adult-model of healthcare and promote independent access to healthcare (U.S. Department of Health and Human Services, 2008). These services are beneficial in improving patient's healthcare knowledge, decision-making skills, and health-rated quality of life (Lotstein et al., 2008; McDonagh et al., 2006). Although caregivers are an asset to the physician's ability to treat a patient with ASD, they may not always be present during appointments. Participants in the current study indicated that direct support providers of patients in residential facilities are often not present or are not able to provide extensive background information. Thus, physicians cannot ultimately rely on caregivers' assistance and/or information and must build a readily available set of skills to treat this patient population independently.

Another commonly identified theme was the lack of formal medical training specific to ASD. This finding is consistent with the literature demonstrating that healthcare providers lack sufficient skills and knowledge related to providing healthcare to patients with ASD (Zerbo et al., 2015). Although Zerbo and colleagues (2015) significantly contributed to the literature on understanding healthcare provided to patients with ASD, the overall sample included a wide range of providers and focused on the identification of ASD, comfort level in treating this patient population, and training gaps and needs in delivering healthcare services to adult patients with ASD. The current study included exclusively medical trainees and physicians to identify specific recommendations and areas of need within medical care, specifically hospital environments. A primary focus of the current study was also to specifically examine physicians' response to severe behavior and experiences with restraint in hospital patients with ASD. The implications of the current study suggest that formal training on ASD is needed beyond simply understanding of the diagnostic criteria. Although results of the ASK-Q indicated overall adequate ASD knowledge for both medical trainees and physicians, there is a distinction between identifying or describing core features of ASD and having practical knowledge in how to best address these features within a hospital setting. Qualitative results are in direct support of this claim as physicians reported a lack of training and knowledge in how to appropriately respond to and manage severe behavior in patients with ASD. Results demonstrated that physicians had higher overall knowledge of ASD than medical trainees as evidenced by higher scores in the four subscales of the ASK-Q. Physicians may be better able to recognize the core features of ASD simply due to increased experience treating patients with ASD presenting at the

hospital. Results demonstrated that several medical trainees endorsed stigma on the ASK-Q. This finding is consistent with the qualitative data indicating negative perceptions of treating patients with ASD, such as appointments being more time-consuming and difficult than appointments with their neurotypical peers. Future research is needed on how specialized training may improve the standard of hospital care for patients with ASD across the lifespan and decrease potential stigma associated with treating this population.

As the prevalence of ASD is increasing nation-wide (Christensen et al., 2019), physicians may be treating an increasing number of patients with ASD. Given that hospital environments may be challenging for this patient population, there is significant need for medical trainees and physicians to continue to develop their technical knowledge of ASD and non-technical skills (e.g., communication, environmental adaptations) to best treat patients with ASD and severe behavior. One suggestion to improve training provided by a medical trainee included expanding simulated patient training to portray patients with ASD. Simulated patients are trained actors used to portray a predetermined set of symptoms or a specific diagnosis (Kaplonyi et al., 2017; Williams & Song, 2019). In a systematic review, researchers found that simulated patients are effective in allowing medical trainees to practice and refine non-technical clinical skills, including communication (Kaplonyi et al., 2017). More recently, a scoping review examined the effectiveness of simulated patients in three domains (i.e., technical, non-technical, and cognitive skills), and approximately 73% of studies included were deemed effective in improving trainee's clinical competence (Williams & Song, 2019).

Given their effectiveness in training, a standardized patient that accurately portrays the core features of ASD may build physician competency and comfort in

treating this unique patient population. For instance, a simulated patient may act out a patient's sensitivity to bright lights and the busy hospital environment by covering their ears, shutting their eyes, and not responding to the physician. Additionally, that same patient with ASD may also engage in head-banging due to heightened sensory sensitivities within the hospital environment. A simulated patient may display instances of severe behavior to facilitate medical trainees' response and communication skills with the patient and caregivers. Strategic exposure to different presentations and features of ASD that may manifest during hospital visits have the potential to teach physicians how to quickly adapt their approach to be suitable for patients diagnosed with or demonstrating behaviors consistent with ASD, such as altering the physical environment or their approach including dimming the exam room lights or talking in a quieter tone. A well-informed physician that promotes positive patient interactions may proactively decrease the occurrence of severe behavior or reduce the occurrence of reactive restraint in hospital settings. A review by Wilson and Peterson (2017) found that patients and their caregivers are likely to report a positive medical experience when physicians have ASD-specific knowledge, provide detailed explanations of the exam or procedure, and use positive reinforcement. Researchers explained that the successful implementation of these strategies decreased challenges related to the medical environment, and thus reduced instances of severe behavior. Taken together, the proactive use of these strategies by medical trainees and physicians has the potential to improve patient-physician and caregiver-physician interactions and reduce the need for restraint within hospital settings.

In addition, many themes discussed by participants related to why severe behavior occurs and hypothesized predictors of severe behavior, including diagnosis and factors

related to the environment. Most significantly, medical trainees and physicians did not present a strong understanding of behavioral function, as evidenced by attributing severe behavior to internal (e.g., maintaining inner peace) and external (e.g., physical environment) factors. Although some of the external factors and reported experiences mentioned by physicians (e.g., hospital environment as loud, atypical routine) are helpful in understanding behavioral function, internal factors described by participants do not readily inform intervention. For instance, a physician attributing property destruction to a patient's need to maintain "inner peace" is not necessarily helpful in the moment they must respond. Rather, proper behavioral training may teach them to identify antecedents to severe behavior and maintaining consequences, as well as how to safely respond in an efficient and time-sensitive manner. Kupzyk and Allen (2019) reviewed behavioral interventions to increase medical compliance, finding that graduated exposure and contingent reinforcement are most commonly used followed by modeling and prompting, and distraction. Although behavioral function originated from the field of behavior analysis, the incorporation of function-based treatment is an important contribution to medical training. If a physician can learn to conceptualize why severe behavior may occur, this understanding may inform how they navigate treatment. For instance, if a physician suspects a patient's severe behavior to be maintained by escape from an unfamiliar medical procedure, they may consider adapting their approach such as presenting fewer demands during a patient's physical exam, slowly introducing each step of the medical procedure, or having their caregiver provide a naturally occurring reward to incentivize appropriate behavior and compliance with medical treatment. Although the behavioral literature has widely examined behavioral interventions for increasing

compliance with medical procedures (e.g., Kupzyk & Allen, 2019; Riley & Freeman, 2019), this study extended the literature to examine physician experiences with management of severe behavior during acute care appointments. Future research is needed to investigate the effects of increasing physician knowledge of behavioral function on their approach to severe behavior during hospital visits.

Participants also described the documentation procedures of restraint, which were reported to be primarily completed by the attending physician. Participants reported that the physician is responsible for documenting the justification for restraint, restraint type, and follow-up assessment. However, some physicians explained that nurses often are helpful in reminding physicians to complete assessment procedures and subsequent documentation. In addition, the documentation process described by participants did not mention comprehensive information, including (a) restraint duration; (b) response to restraint, including that of caregivers and surrounding patients; and (c) if/when a post-restraint explanation was provided. The literature has started to investigate caregiver perspectives on electronic health records for patients with ASD, finding that they are not often reviewed by caregivers (Bush et al., 2016). However, the usability of the documentation system for severe behavior and restraint and accessibility for caregivers have not been investigated.

Another frequently endorsed theme across participants was the limitations to their electronic medical system. The burgeoning field of medical informatics aims to bridge clinical research and practice within healthcare settings, such as focusing on improved documentation systems and graduate education (e.g., Kulikowski et al., 2012). Researchers defined core competencies of the field to facilitate information technology

and how that may impact delivery of patient care, suggesting that there is room for improvement across various healthcare settings. Participants in the current study discussed occasionally missing an important patient progress note due to time constraints and the abundance of available notes for review. Although a comprehensive documentation review prior to the patient appointment is likely to assist with treatment planning and a coordinated response for a variety of presenting concerns, physician time is extremely limited. As a result, flagging systems designed to alert the physician to a particular presenting concern or diagnosis have been adopted by many healthcare systems (e.g., van Staa et al, 2014). However, the current study demonstrated that the flagging system for severe behavior is inconsistent. Participants described that, for a particular patient's record to be flagged, this requires special paperwork and processing through institutional departments which can be unnecessarily time consuming for physicians. Recommendations for the future include revising the documentation system to include a comprehensive flagging system that can easily draw a physician's attention to a patient's history of severe behavior and ASD diagnosis. Participants also discussed the "problems list" section of the electronic health record as key in their documentation review. In this section, the patient's current diagnoses and concerns are listed in one, easily accessible list. Although this list was frequently used by participants, inconsistencies were noted in updating the patient's problem list as needed by resolving past diagnoses (i.e., clicking a symbol to hide the outdated diagnosis from the patient's current problem list). With regard to the abundance of notes for patients who may regularly visit the hospital system, the use of unified smartphrases (i.e., note templates) can ease the burden of the documentation system across hospital departments. If the documentation process is

standardized, physicians may more easily focus on relevant pieces of documentation within a patient's electronic file.

Interestingly, our participants' use of chemical restraint was most often described as a means to proactively manage characteristics of ASD or to facilitate completion of medical procedures. Whereas Friedman and Crabb (2018) described the use of chemical restraint as a means to manage severe behavior reactively, chemical restraint within our sample of participants appeared to represent proactive rather than reactive management of perceived severe behavior. The interpretation of our data is in direct alignment with Kirwan and Coyne (2017), which reported that among pediatric populations the perception and use of restraint is to proactively facilitate safe medical procedures. Terminology of "chemical restraint" used by researchers may have led to different responses from medical trainees and physicians who may describe the reactive medication administration as medicating emergent behaviors.

Although the facilitators strived to create a welcoming and non-judgmental environment, authors recognize restraint may be a controversial and uncomfortable topic for physicians, and this may have affected focus group and/or interview responses. Participants may have hesitated to elaborate on open-ended questions due to a desire to present as competent and using evidence-based clinical practice (i.e., not endorsing overuse of restraint). In order to reduce potential medical trainee and physician discomfort, discussion topics asked participants to report their experiences and/or observed experiences of others without needing to take ownership of treatment decisions that may be negatively perceived by others. To promote participation from medical trainees and physicians alike, we separated participants into medical trainee and

physician groups. The justification for this approach was to facilitate medical trainees'

discussion of observed or personal negative perceptions and experiences, and to identify

potential improvements in an environment where supervisors or those of a higher power

differential were not present.

A limitation of this study is that the majority of the sample consisted of medical

trainees. We experienced significant difficulties in recruiting early-career physicians,

resulting in a larger representation of medical students and easier access to that

population. This difficulty in physician recruitment may have been attributed to

additional stressors placed on physicians during the COVID-19 pandemic, potentially

resulting in physician burnout and decreased availability or willingness to participate in

research outside of scheduled patient hours. Regardless, the themes that emerged between

medical trainees and physicians were largely consistent. Our sample is consistent with

past medical research that has relied heavily on medical trainees. According to Gould et

al. (2002), medical trainees are a valuable population to target in the quality improvement

of medical research and practice, and are widely studied to represent the larger medical

population. Compared to national physician demographics, our sample included a larger

percentage of female and racial/ethnic minority participants (Association of American

Medical Colleges, 2019). Future investigations should consider expanding inclusion

criteria to physicians with additional years of clinical experience as more clinical

exposure may increase practical knowledge and skills related to the treatment of severe

behavior and ASD.

Although successful hospital restraint reduction programs have been documented

in the literature (e.g., Cosper et al., 2015; Duxbury et al., 2019) and the need to reduce

restraint use for patients with ASD has been established (O'Donoghue et al., 2020; Sturmey, 2018), the broader goal of this study was to gather information to inform future efforts to optimize healthcare for patients with ASD across the lifespan. The first step to optimizing healthcare included gathering information related to medical trainees' and physicians' experiences treating patients with ASD, knowledge of ASD and behavioral function, restraint implementation, policies and protocols, and perceived needs. Perceived needs and gaps in knowledge gleaned from this exploratory research will shape training and education efforts to optimize healthcare for patients with ASD across the lifespan. This study also identified the current state of physician experiences with ASD and severe behavior management and institutional policies (e.g., documentation, restraint) at one urban teaching hospital. Results identified clear areas for improvements at this particular institution that may generalize to other healthcare systems due our inclusion of multiple core target departments and a hospital system serving a diverse geographic region. The themes that emerged from participant narratives and their salience serve to guide future research efforts in this necessary area to increase compassionate treatment of patients with ASD across the lifespan.

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Tables and Figures

Table A1

Demographics

Variable	*N*	%
Gender		
Female	17	68.00
Male	8	32.00
Race		
White	13	52.00
Asian	5	20.00
Hispanic	4	16.00
African American	3	12.00
Status		
Student	18	72.00
Resident	4	16.00
Physician	3	12.00
Department		
Pediatrics*	20	80.00
Neurology*	19	76.00
Psychiatry*	19	76.00
Emergency Medicine*	18	72.00
Surgery	19	76.00
Internal Medicine	19	76.00
Family Medicine	18	72.00
OB/GYN	16	64.00
Pediatric Emergency	4	16.00
Anesthesia	2	8.00
Student Clinic	2	8.00
NICU	2	8.00
Integrative Medicine	1	4.00
PICU	1	4.00
Radiology	1	4.00
Ultrasound	1	4.00
Urology	1	4.00

Note. Department = all current departments/rotations completed; OB/GYN =

Obstetrics/Gynecology; NICU = neonatal intensive care unit; PICU = pediatric intensive

care unit. Asterisk indicates departments targeted during recruitment. Participants could

endorse multiple departments to represent current placement or rotations completed.

Table A2

Theme Numbers and Descriptions

Theme	Description
1	Trainees are not responsible for managing severe behavior and implementing restraint, and were thus unfamiliar with comprehensive restraint protocols.
2	Trainees described or suggested alternative strategies used by themselves or others for treating patients with ASD and severe behavior.
3	Trainees expressed negative reactions or assessments of restraint by trainees themselves, physicians, caregivers, and patients.
4	Trainees reported the helpful role of patient's caregivers during appointments for the management of severe behavior.
5	Trainees expressed limited experience treating patients with ASD and experience varying by hospital department, thus contributing to perceived more successful patient interactions and treatment of patients with ASD.
6	Trainees identified internal characteristics as the reason why severe behavior may occur in patients with ASD.
7	Trainees identified a lack of formal training related to treating patients with ASD.
8	Trainees reported specific observable patient characteristics as a predictor to restraint implementation.
9	Trainees identified external characteristics related to the patient's environment and background that are not readily observable, and factors not related to the patient as a predictor to restraint.
10	Trainees reported limitations of current institutional policies that affect their service deliver for patients with ASD who engage in severe behavior.
11	Trainees expressed a negative perception and/or evaluation of severe behavior in medical settings.
12	Trainees reported a lack of knowledge, training, and experience related to crisis management and protocols, which may vary by department.
13	Trainees expressed higher tolerance and different response to severe behavior in patients with ASD compared to those without ASD.
14	Trainees reported a decision-making approach or algorithm for deciding whether to respond to severe behavior and implement restraint.
15	Trainees expressed inconsistent documentation and limitations to the electronic medical health system that affect service delivery.
16	Trainees identified external causes related to the environment and the role of others as the reason why severe behavior may occur.
17	Trainees distinguished and described differences between types of severe behavior.
18	Trainees described using medication as a proactive strategy for treating patients with ASD and severe behavior.
19	Trainees expressed negative perceptions about treating patients with ASD held by themselves or observed by other professionals.

Theme	Description
20	Trainees described knowledge consistent with the core features of ASD and experience with presenting features during their limited interactions treating patients with ASD.

Table A3

Frequency and Percentage of Overall and Individual Themes by Participant Status

| | Medical Trainees | | | | | | | | Physicians | | | | | | | |
| | Overall | | FG A | | FG B | | FG C | | Overall | | Int. 1 | | Int. 2 | | Int. 3 | |
Theme	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
1	60	12.40	25	16.56	21	12.21	14	8.70	19	10.22	3	6.00	8	11.27	8	12.31
2	48	9.92	8	5.30	19	11.05	21	13.04	17	9.14	5	10.00	8	11.27	4	6.15
3	40	8.26	7	4.64	22	12.79	11	6.83	22	11.83	0	0.00	15	21.13	7	10.77
4	36	7.44	5	3.31	6	3.49	25	15.53	16	8.60	9	18.00	5	7.04	2	3.08
5	29	5.99	7	4.64	8	4.65	14	8.70	4	2.15	1	2.00	1	1.41	2	3.08
6	28	5.79	9	5.96	10	5.81	9	5.59	6	3.23	1	2.00	4	5.63	1	1.54
7	28	5.79	8	5.30	13	7.56	7	4.35	9	4.84	5	10.00	3	4.23	1	1.54
8	27	5.58	14	9.27	7	4.07	6	3.73	23	12.37	4	8.00	7	9.86	12	18.46
9	25	5.17	7	4.64	13	7.56	5	3.11	6	3.23	0	0.00	5	7.04	1	1.54
10	23	4.75	7	4.64	9	5.23	7	4.35	10	5.38	5	10.00	2	2.82	3	4.62
11	19	3.93	6	3.97	3	1.74	10	6.21	5	2.69	1	2.00	2	2.83	2	3.08
12	17	3.51	8	5.30	5	2.91	4	2.48	8	4.30	2	4.00	2	2.83	4	6.15
13	14	2.89	6	3.97	2	1.16	6	3.73	4	2.15	1	2.00	0	0.00	3	4.62
14	14	2.89	5	3.31	6	3.49	3	1.86	7	3.76	0	0.00	3	4.23	4	6.15
15	13	2.69	6	3.97	3	1.74	4	2.48	13	6.99	6	12.00	2	2.82	5	7.69
16	13	2.69	5	3.31	5	2.91	3	1.86	4	2.15	0	0.00	1	1.41	3	4.62

| | Medical Trainees | | | | | | | | Physicians | | | | | | | |
| | Overall | | FG A | | FG B | | FG C | | Overall | | Int. 1 | | Int. 2 | | Int. 3 | |
Theme	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
17	13	2.69	3	1.99	10	5.81	0	0.00	2	1.08	1	2.00	1	1.41	0	0.00
18	13	2.69	4	2.65	0	0	9	5.59	2	1.08	1	2.00	0	0.00	1	1.54
19	12	2.48	2	1.32	8	4.65	2	1.24	3	1.61	3	6.00	0	0.00	0	0.00
20	12	2.48	9	5.96	2	1.16	1	0.62	6	3.23	2	4.00	2	2.82	2	3.08

Note. FG = focus group; Int = interview; # = number of occurrences; % = percent of total occurrences.

Table A4

Focus Group A Salience of Themes by Medical Trainee

	P1		P2		P3		P4		P5		P6		P7	
Theme	#	%	#	%	#	%	#	%	#	%	#	%	#	%
1	2	10.53	2	9.52	1	4.76	0	0.00	7	20.59	0	0.00	13	27.66
2	1	5.26	2	9.52	2	9.52	1	25.00	1	2.94	1	20.00	0	0.00
3	1	5.26	0	0.00	0	0.00	0	0.00	1	2.94	1	20.00	4	8.51
4	0	0.00	2	9.52	0	0.00	0	0.00	2	5.88	0	0.00	1	2.13
5	1	5.26	1	4.76	2	9.52	0	0.00	1	2.94	0	0.00	2	4.26
6	0	0.00	1	4.76	3	14.29	0	0.00	1	2.94	0	0.00	1	2.13
7	1	5.26	0	0.00	1	4.76	1	25.00	2	5.88	0	0.00	3	6.38
8	4	21.05	1	4.76	2	9.52	0	0.00	2	5.88	0	0.00	5	10.64
9	0	0.00	2	9.52	1	4.76	0	0.00	0	0.00	0	0.00	1	1.23
10	2	10.53	1	4.76	0	0.00	1	25.00	3	8.82	0	0.00	2	4.26
11	2	10.53	1	4.76	1	4.76	0	0.00	3	8.82	2	40.00	0	0.00
12	1	5.26	1	4.76	0	0.00	1	25.00	0	0.00	0	0.00	3	6.38
13	1	5.26	1	4.76	1	4.76	0	0.00	1	2.94	0	0.00	2	4.26
14	0	0.00	0	0.00	0	0.00	0	0.00	2	5.88	0	0.00	3	6.38
15	2	10.53	0	0.00	1	4.76	0	0.00	2	5.88	0	0.00	1	2.13
16	1	5.26	1	4.76	0	0.00	0	0.00	1	2.94	0	0.00	2	4.26

Theme	P1		P2		P3		P4		P5		P6		P7	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
17	0	0.00	2	9.52	0	0.00	0	0.00	0	0.00	1	20.00	0	0.00
18	0	0.00	0	0.00	2	9.53	0	0.00	0	0.00	0	0.00	2	4.26
19	0	0.00	0	0.00	0	0.00	0	0.00	1	2.94	0	0.00	1	2.13
20	0	0.00	2	9.52	4	19.05	0	0.00	2	5.88	0	0.00	1	2.13

Note. P = participant; # = number of occurrences; % = percent of total occurrences. Asterisk indicates participant with partial

data.

Table A5

Focus Group B Salience of Themes by Medical Trainee

Theme	P8 #	P8 %	P9 #	P9 %	P10 #	P10 %	P11 #	P11 %	P12 #	P12 %	P13 #	P13 %	P14 #	P14 %	P15 #	P15 %
1	1	5.88	12	17.65	3	12.00	2	10.00	0	0.00	0	0.00	0	0.00	3	25.00
2	1	5.88	6	8.82	6	24.00	4	20.00	0	0.00	2	18.18	0	0.00	0	0.00
3	4	23.53	10	14.71	2	8.00	1	5.00	2	14.29	0	0.00	0	0.00	3	25.00
4	1	5.88	3	4.41	1	4.00	0	0.00	0	0.00	1	9.09	0	0.00	0	0.00
5	2	11.76	2	2.94	1	4.00	3	15.00	0	0.00	0	0.00	0	0.00	0	0.00
6	1	5.88	1	1.47	2	8.00	0	0.00	2	14.29	1	9.09	0	0.00	2	16.67
7	2	11.76	3	4.41	1	4.00	2	10.00	2	14.29	2	18.18	0	0.00	0	0.00
8	1	5.88	3	4.41	2	8.00	0	0.00	1	7.14	0	0.00	1	5.00	0	0.00
9	0	0.00	7	10.29	3	12.00	1	5.00	2	14.29	0	0.00	0	0.00	0	0.00
10	0	0.00	3	4.41	0	0.00	3	15.00	0	0.00	1	9.09	0	0.00	2	16.67
11	0	0.00	2	2.94	0	0.00	0	0.00	1	7.14	0	0.00	1	5.00	0	0.00

Theme	P8		P9		P10		P11		P12		P13		P14		P15	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
12	3	17.65	2	2.94	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
13	0	0.00	1	1.47	1	4.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
14	0	0.00	2	2.94	0	0.00	0	0.00	3	21.43	0	0.00	0	0.00	0	0.00
15	0	0.00	2	2.94	0	0.00	1	5.00	0	0.00	0	0.00	1	5.00	0	0.00
16	0	0.00	3	4.41	0	0.00	1	5.00	0	0.00	1	9.09	0	0.00	0	0.00
17	1	5.88	2	2.94	3	12.00	0	0.00	0	0.00	2	18.18	1	5.00	0	0.00
18	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
19	0	0.00	3	4.41	0	0.00	2	10.00	1	7.14	1	9.09	0	0.00	1	8.33
20	0	0.00	1	1.47	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	1	8.33

Note. P = participant; # = number of occurrences; % = percent of total occurrences.

Table A6

Focus Group C Salience of Themes by Medical Trainee

	P16		P17		P18		P19		P20		P21		P22	
Theme	#	%	#	%	#	%	#	%	#	%	#	%	#	%
1	0	0.00	2	7.14	2	6.67	0	0.00	4	11.76	6	13.33	0	0.00
2	2	15.38	3	10.71	7	23.33	0	0.00	3	8.82	5	11.11	1	20.00
3	1	7.69	2	7.14	2	6.67	0	0.00	3	8.82	3	6.67	0	0.00
4	1	7.69	2	7.14	7	23.33	2	33.33	3	8.82	10	22.22	0	0.00
5	2	15.38	2	7.14	1	3.33	2	33.33	2	5.88	4	8.89	1	20.00
6	1	7.69	3	10.71	0	0.00	0	0.00	4	11.76	0	0.00	1	20.00
7	2	15.38	2	7.14	2	6.67	0	0.00	0	0.00	1	2.22	0	0.00
8	0	0.00	2	7.14	2	6.67	0	0.00	1	2.94	1	2.22	0	0.00
9	0	0.00	0	0.00	0	0.00	0	0.00	3	8.82	1	2.22	1	20.00
10	1	7.69	0	0.00	2	6.67	1	16.67	1	2.94	2	4.44	0	0.00
11	0	0.00	2	7.14	2	6.67	1	16.67	3	8.82	1	2.22	1	20.00
12	1	7.69	1	3.57	1	3.33	0	0.00	0	0.00	1	2.22	0	0.00
13	0	0.00	1	3.57	0	0.00	0	0.00	3	8.82	2	4.44	0	0.00
14	0	0.00	1	3.57	1	3.33	0	0.00	0	0.00	1	2.22	0	0.00
15	0	0.00	1	3.57	1	3.33	0	0.00	1	2.94	1	2.22	0	0.00
16	0	0.00	0	0.00	0	0.00	0	0.00	1	2.94	2	4.44	0	0.00

Theme	P16		P17		P18		P19		P20		P21		P22	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
17	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
18	1	7.69	1	3.57	0	0.00	0	0.00	2	5.88	4	8.89	0	0.00
19	1	7.69	1	3.57	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
20	0	0.00	1	3.57	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00

Note. P = participant; # = number of occurrences; % = percent of total occurrences.

Table A7

Salience of Themes by Physician

	P23		P24		P25	
Theme	#	%	#	%	#	%
1	3	6.00	8	11.27	8	12.31
2	5	10.00	8	11.27	4	6.15
3	0	0	15	21.13	7	10.77
4	9	18.00	5	7.04	2	3.08
5	1	2.00	1	1.41	2	3.08
6	1	2.00	4	5.63	1	1.54
7	5	10.00	3	4.23	1	1.54
8	4	8.00	7	9.86	12	18.46
9	0	0	5	7.04	1	1.54
10	5	10.00	2	2.82	3	4.62
11	1	2.00	2	2.82	2	3.08
12	2	4.00	2	2.82	4	6.15
13	1	2.00	0	0	3	4.62
14	0	0	3	4.23	4	6.15
15	6	12.00	2	2.82	5	7.69
16	0	0	1	1.41	3	4.62
17	1	2.00	1	1.41	0	0
18	1	2.00	0	0	1	1.54
19	3	6.00	0	0	0	0
20	2	4.00	2	2.82	2	3.08

*Note.* P = participant; # = number of occurrences; % = percent of total occurrences.

Table A8

ASK-Q Mean and Percentage of Adequate Results by Participant Status

Status	Diagnosis/ Symptoms		Etiology		Treatment		Stigma		Total Score	
	Mean	%	*Mean*	%	*Mean*	%	*Mean*	%	*Mean*	%
Trainees	15.21	100	12.36	80.95	12.34	90.48	0.91	90.48	39.91	95.24
Physicians	15	100	14.67	100	13.33	100	0.33	100	43	100

Note. % = percent of adequate scores; maximum score per subscale: diagnosis/symptoms

= 18, etiology = 16, treatment = 14, stigma = 7, total score = 48.

Figure A1

ASK-Q Results
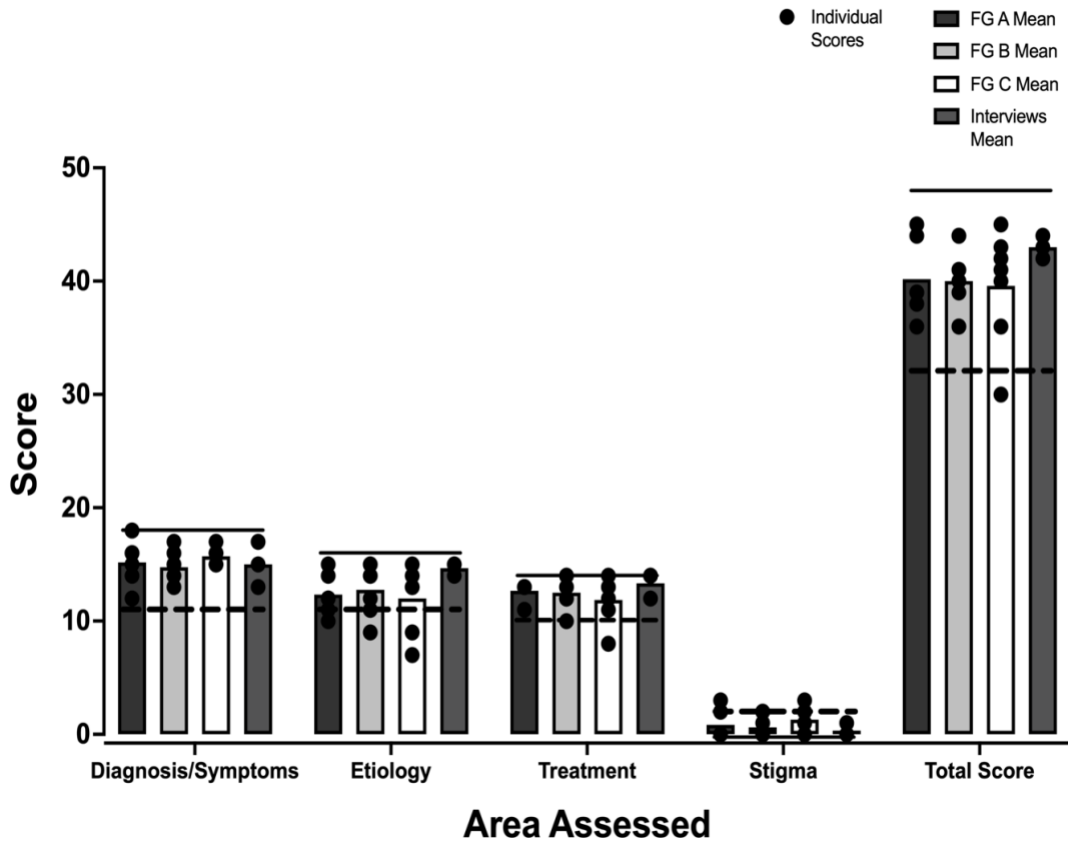
Note. FG = focus group; Solid line = maximum score; Dashed line = adequate score.