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**HOSPITAL PROVIDER KNOWLEDGE OF BEHAVIORAL FUNCTION AND  
MANAGEMENT OF SEVERE BEHAVIOR FOR PATIENTS WITH AUTISM**

by  
Giovanna Salvatore DeVito, Ph.D.

A Dissertation

Submitted to the  
Department of Psychology  
College of Science and Mathematics  
In partial fulfillment of the requirement  
For the degree of  
Doctor of Philosophy  
at  
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## **Abstract**

Giovanna L. Salvatore, M.A.

### **HOSPITAL PROVIDER KNOWLEDGE OF BEHAVIORAL FUNCTION AND MANAGEMENT OF SEVERE BEHAVIOR FOR PATIENTS WITH AUTISM 2023-2024**

Christina A. Simmons, Ph.D., BCBA-D  
Doctor of Philosophy

Hospital patients with autism spectrum disorder<sup>1</sup> may engage in various topographies of severe behavior, with higher rates of restraint implemented than for their neurotypical counterparts. Multidisciplinary behavior management teams were developed to decrease restraint across general hospital patients. In Study 1, the Knowledge of Behavioral Function survey measure was developed and administered to physicians and trainees. Results indicated low knowledge of behavioral function, with a mean percent correct of 66.60% on close-ended items and 14% correct on open-ended vignette items. Years of experience and discipline were each not significantly associated with knowledge of behavioral function. Despite low function-based knowledge, 91.10% of participants demonstrated adequate knowledge of autism and these scores were not significantly correlated. In Study 2, discussions with behavioral management team members highlighted differences in team purposes, procedures, and training across hospitals. Although participants still described using restraint, they considered alternatives and indicated areas for future training. Study findings may inform development of ASD-focused, function-based training to improve hospital standard of care for autistic patients.

*Keywords:* Severe behavior, autism, behavioral function, hospital

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<sup>1</sup> We are using ASD to align with the current diagnostic label in the Diagnostic and Statistical Manual of Mental Health Disorders, 5<sup>th</sup> Edition, Text Revision. We fully support individualized use of language that aligns with individuals' and families' preferences.

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## **Chapter 1**

### **Introduction**

Autism spectrum disorder (ASD) is a neurodevelopmental disorder present across the lifespan. Per the Diagnostic and Statistical Manual of Mental Health Disorders, 5<sup>th</sup> Edition, Text Revision (DSM-5-TR; American Psychological Association [APA], 2022), core features of ASD include differences in social communication and the presence of restricted, repetitive behaviors and interests. Prevalence data indicate that ASD is increasing nationwide, affecting 1 in 36 individuals (Maenner et al., 2023). In addition to experiencing and interacting with their environment in unique ways, individuals with ASD may present with co-occurring health concerns across physical, mental, or behavioral health domains. Common physical conditions that co-occur with ASD include epilepsy and gastrointestinal disorders (Matson & Goldin, 2013). Autistic individuals may also experience mental health concerns, such as attention deficit/hyperactivity disorder (ADHD), anxiety and mood disorders (Davis & Kollins, 2012; Rosen et al., 2018) and behavioral health concerns, such as the occurrence of severe behavior (Steenfeldt-Kristensen et al., 2020) at higher rates than those without autism. Given that these physical, mental, and behavioral health concerns can impact the well-being of autistic individuals, it is important for this patient population to receive high quality supports in healthcare settings.

Individuals with ASD seek medical treatment at disproportionate rates across the lifespan compared to those without ASD. The literature on trends and patterns of hospital visits for patients with ASD has predominately focused on pediatric and adolescent patients (e.g., Liu et al., 2017; Mandell, 2008; Straus et al., 2019). Research suggests that



children with ASD visit hospitals more often than their neurotypical peers (Mandell, 2008). Within a sample of adolescents over a 9-year period, Liu et al. (2017) indicated that autistic individuals were four times more likely to visit the emergency department than those without ASD. Although adults with ASD have arguably increased healthcare needs (e.g., Magiati et al., 2014), there is a lack of prevalence data documenting overall trends of hospital utilization within this patient population. Further, the current research is restricted to specific hospital departments, such as the emergency department. One study found that adults with ASD were more likely to utilize emergency department services than those without ASD (Nicolaidis et al., 2013). Vohra et al. (2016) demonstrated that adults with ASD commonly visit the emergency department due to mental health concerns and injury, and that adults with ASD were two times more likely to use emergency services than those without ASD. Taken together, higher hospitalization rates for individuals with ASD are likely due to the presence of co-occurring health concerns.

Severe behavior is highly prevalent in individuals with ASD as compared to their neurotypical peers (Newcomb & Hagopian, 2018). Severe behavior may include physical and verbal aggression, elopement, self-injurious behavior, and property destruction (Kennedy Krieger Institute, 2021). Prevalence estimates of unsafe and interfering behavior in individuals with ASD vary widely, ranging from 8% to 68% (Hill et al., 2014). This wide range in prevalence of severe behavior may be attributed to several factors, such as definition of severe behavior, samples including primarily children, and reliance on parental report (e.g., Kanne & Mazurek, 2011). More intense occurrences of severe or interfering behavior may result in hospitalization of individuals with ASD. For instance, severe head-banging may cause injury that results in seeking medical care.

Hospital settings can be challenging environments for individuals with ASD due to core features of autism described in the DSM-5-TR (APA, 2022). In the domain of social communication, autistic patients may experience challenges with social communication, such as providing a succinct explanation of their symptoms while maintaining eye contact with a novel healthcare provider. In addition, patients with autism may have different sensory needs and preferences, such as heightened sensitivity to the bright lights and loud noises that are common in hospitals or to provider touch during routine physical examinations. Autistic patients may also have preferences for routine and predictability and, subsequently, may experience challenges navigating fast-paced unpredictable situations or transitioning across hospital rooms or departments. Further, healthcare providers experience challenges in meeting the unique needs of autistic patients and have suggested systemic changes such as improved pre-admission plans describing patients' strengths, needs, and preferences (Muskat et al., 2015).

There is an abundance of literature examining the quality of healthcare received by autistic patients and their families. Focus group discussions including youth with ASD, caregivers and families, and healthcare providers (i.e., nurses, physicians, speech language pathologists) identified common barriers to adequate hospital care for patients with ASD, including the expectation to communicate, follow an unpredictable schedule, and cope with various sensory input. Healthcare providers also identified challenges within their hospital teams (e.g., poor or ineffective communication, too many providers present) and within hospital systems more broadly (e.g., lack of ASD-specific resources and competence; Muskat et al., 2015). Such challenges may increase the likelihood of patients with ASD engaging in different topographies of severe behavior during a

hospital visit. For instance, if patients experience difficulty communicating their needs in a way that is understood by healthcare providers, they may engage in severe behavior to gain access to something desired or to escape or avoid an unpleasant situation. The routine and sensory preferences of individuals with autism, combined with characteristics of the hospital environment, could also contribute to the occurrence of severe behavior. For instance, the unpreferred demands of an upcoming medical procedure may result in the occurrence of property destruction to terminate this unpleasant situation. Altogether, the environmental variables within a hospital may be more likely to evoke severe behavior for patients with ASD compared to their neurotypical counterparts (Siegel & Gabriels, 2014).

Severe behavior in the hospital may result in a variety of adverse consequences for the patient and others. For example, severe behavior may jeopardize the health and safety of patients and providers in the surrounding environment (Lelonek et al., 2018). The occurrence of severe behavior, such as self-injury, elopement, and aggression, can pose harm or increased risk of injury to oneself and/or others, and topographies such as destructive behavior can cause damage to property (Kanne & Mazurek, 2011; Newcomb & Hogopian, 2018). In addition, there is a wide variety of evidence documenting the adverse effects of hospital patient severe behavior on provider outcomes (Adriaenssens et al., 2015; Lanctôt & Guay, 2014). Repeated instances of severe behavior across hospital patients with ASD may decrease occupational satisfaction and burnout among hospital providers (Lanctôt & Guay, 2014). Further, hospitals may incur increased costs to manage and prevent patients' severe behavior, including increased security and staff

training efforts (Yost et al., 2021). As a result, a variety of strategies have been designed to reduce adverse consequences associated with hospital patients' severe behavior.

Restraint (i.e., physical, mechanical, chemical) is a behavior management strategy widely implemented across hospitals, patient diagnoses, and topographies of severe behavior. *Physical restraint* refers to the use of physical positioning or holds 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* is the administration 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). However, restraint does not come without risks to the patient, their families, and medical providers. Restraint may adversely affect the patient's physical health (e.g., risk of injury, functional decline, death; Evans & Cotter, 2008) and mental or psychological health (e.g., increased risk of mental health diagnoses, like post-traumatic stress disorder, as a result of restraint implementation). Restraint may also increase medical distrust and contribute to a lack of patient autonomy (Wong et al., 2020).

Further, restraint may be perceived negatively by medical providers, caregivers, and patients alike. Focus groups conducted by Salvatore et al. (2021) found that medical trainees and physicians prefer to avoid restraint implementation and remove restraint once applied, observe sad and/or uncomfortable reactions to restraint from patients and caregivers, and perceive restraint as nonhuman. Although the risks and negative perceptions of restraint have been documented, restraint implementation continues in hospital settings (e.g., Doehring et al., 2014; Lunskey et al., 2018; O'Donoghue et al.,

2020). For example, pre-adolescent psychiatric inpatients with ASD and co-occurring intellectual disability (ID) experience elevated rates of restraint and seclusion (78%) compared to autistic patients without ID (50%), and patients with neither diagnosis (35%; O'Donoghue et al., 2020). Despite this difference in restraint by diagnosis, the listed rates of restraint and seclusion are extremely high for autistic patients. In a review of emergency department experiences of patients with ASD, parental report indicated that adolescent and adult patients with ASD experienced restraint and seclusion 31% of the time. Physical restraints were used 18.5% of visits, chemical restraint was used 24.5% of visits, and both were used during 12.2% of emergency department visits. For the remainder of cases, seclusion was used (51%; Lunskey et al., 2018). Within children with ASD who experience inpatient hospitalization, restraint implementation is common to facilitate completion of medical procedures (Johnson & Rodriguez, 2013). A review of unsafe and interfering behavior within children and adolescents with ASD across inpatient, residential, and other settings (i.e., home, school) indicated that 19% of unsafe and interfering behavior was labeled as severe, requiring the use of seclusion, restraint, and protective equipment (Doehring et al., 2014). This evidence of medical provider reliance on restraint further emphasizes the need to develop proactive behavior management strategies rather than reactive strategies (i.e., restraint) to best accommodate patients with ASD and severe behavior.

Several initiatives have been piloted within hospitals to safely and effectively prevent and manage severe behavior. These initiatives often include increasing staff education and de-escalation training (Lelonek et al., 2018). Although there are various topographies of severe behavior other than aggression, researchers have primarily

investigated the efficacy of aggressive behavior management training programs. These training programs consistently result in lower incidence of restraint implementation (Livingston et al., 2010), increased provider confidence, and improved attitudes, skills, and knowledge about aggression post-training (Heckemann et al., 2014). Despite their efficacy, education-based programs in the literature are largely designed to meet the needs of specific populations that often do not specifically include patients with ASD and severe behavior (e.g., psychiatric, adult, child populations; Gaynes et al., 2017), or are geared towards training specific types of providers (e.g., nurses; Casey, 2019).

There are few specialized crisis prevention programs documented in the literature that are specifically designed to meet the needs of neurodivergent individuals in healthcare settings. The Marcus Crisis Prevention Program (MCP) was specifically designed for individuals ages 3 to 21 diagnosed with developmental delay who engage in severe behavior. This program was developed to specifically address limitations with existing crisis prevention programs for this population and adheres to best practice recommendations (e.g., focus on prevention, consideration of behavioral function, implementation of least-intrusive procedures). Further, this program includes specific adaptations for training healthcare providers, such as responding to caregiver and visitor behavior and creating a specialized response team. Bernstein and colleagues (2022) indicated that following healthcare staff training with the MCP, staff implemented management techniques more confidently and better communicated as a team during behavioral crises. Most significantly, these effects maintained up to 6-months post-training. Given the success of the MCP, an increasing number of studies are evaluating the adoptability of this training program for a wide range of healthcare settings.

Simulation-based training has been documented to effectively teach medical providers management techniques for specific topographies of behavior. Mitchell et al. (2020) added simulations to acute care pediatric staff's existing annual full-day seminar-based training, consisting of lectures on warning signs of aggression, de-escalation techniques, effective communication strategies, and legislation/local restraint policies. The added training was only 2 hours, consisting of two in-person simulations wherein a trained actor engaged in aggression, targeting providers' use of supportive communication and de-escalation strategies. As a result of the simulations added to the existing seminar-based training, providers' perceived confidence and competence in managing aggressive behavior within pediatric patients with ASD increased. At the 3 to 6-month follow up, 66% of participants self-reported that they had successfully managed patient aggression (Mitchell et al., 2020). In addition, healthcare professionals have role-played the actions of patients exhibiting physical aggression to increase hospital provider attitudes and teamwork in managing behavioral emergencies. These researchers were successful in improving emergency staff's attitudes related to severe behavior through a simulation-enhanced didactic session (Wong et al., 2015). Although aggression is a commonly reported topography of behavior which requires appropriate intervention, there are other topographies of severe behavior that may present within hospitals (e.g., self-injurious behavior, property destruction, verbal aggression, bolting or wandering). Training aimed at increasing hospital providers' effective management strategies for other common topographies of severe behavior has yet to be documented in the literature.

Other ASD-specific hospital initiatives have been created to improve patients' hospital experiences. For instance, autism specific care plans are documents completed

by parents with important information related to their child's communication preferences and strategies, helpful environmental modifications, and safety concerns (Broder-Fingert et al., 2015). These care plans have documented feasibility and improved patient outcomes (e.g., better experience of care, increased healthcare provider attention to ASD-specific needs). Based on needs and barriers in accessing healthcare environments provided by autistic individuals before their appointment, Saqr et al. (2017) created individualized plans to assist autistic patients in completing their medical appointment. Common strategies used in these plans included immediately moving the patient to their room or allowing them to wait in their care upon arrival to the healthcare setting, not conducting vital signs at the time of intake, and providing a notification to patient's before touching them. Similarly, the Autism Support Checklist (ASC) is a questionnaire that measures a patient's communication style, sensory needs, triggers to severe behavior, safety concerns, and potential de-escalation strategies. This information is included in the client's electronic medical record for healthcare providers to access. Preliminary data indicate that hospital providers support the use of the ASC and that it is generally well-received by providers. In-person training has been documented as useful to facilitate healthcare providers accessing and reading the ASC (O'Hagan et al., 2019). As reflected in Salvatore et al. (2021), healthcare providers have limited opportunities to comprehensively review a patient's electronic medical record which may be an ongoing barrier to adopting strategies designed to improve the healthcare provided to patients with ASD and severe behavior. Despite these initiatives to better manage care for patients with ASD, in general, restraint continues to be used in hospitals.



Behavioral rapid response teams (BRRT) were developed to assist healthcare providers with managing behavioral emergencies in hospital settings. According to the literature on these teams, behavioral emergencies consist of a wide variety of target behaviors, including disruptive or threatening behaviors that impact the health and safety of the patient and others (Loucks et al., 2010). The effectiveness of these teams at managing verbal and physical aggression within hospital patients across the United States is documented in the literature (Pestka et al., 2012). The literature also indicates the effectiveness of these teams at decreasing restraint use, reducing reliance on security to implement restraint, reducing provider and/or patient harm, and improving provider confidence at detecting, preventing, and managing severe behavior in the non-psychiatric hospital population (Loucks et al., 2010; Pestka et al., 2012; Zicko et al., 2017). Providers with different expertise are often included on these teams, including nurses, social workers, security, and physicians (Lelonek et al., 2018). On the other hand, specialized teams with varying team members exist to manage medical concerns (e.g., respiratory concern, cardiac arrest; Buist et al., 2002) and psychiatric concerns (e.g., self-harming behaviors, suicidal/homicidal ideation; Carpenter et al., 2013). Although there may be overlap across these teams' responsibilities, BRRT have an increased emphasis on including mental health care workers to prevent and manage hospital patient severe behavior (Zicko et al., 2017).

There are, however, no standardized training or activation systems across BRRT personnel. Salvatierra et al. (2016) demonstrated that the training and practical skills necessary to be a member of these teams are not clearly defined and there are no required credentials to be a member of these teams. Further, these authors indicated that having

knowledge of critical care skills does not directly translate to having excellent behavior management skills. One study analyzed the effectiveness of rapid response team nurses via public health and self-reported survey data, demonstrating that the most effective nurses (i.e., low patient mortality, high nurse job satisfaction and low levels of burnout) have specialized expertise in critical care, an advanced clinical skillset, and greater teaching and collaborative abilities (Aiken et al., 2008). Additionally, the coding systems used to activate these teams also vary widely across hospital settings, such as some using “code green” (Zicko et al., 2017), “code black” (Downes et al., 2009), “code S” (Jones et al., 2012), and “code behavioral rapid response” (Lelonek et al., 2018). The format of how team members are alerted of hospital patient severe behavior also varies, including a private paging system (Zicko et al., 2017) and emergency system that appears to alert the whole hospital via intercom (Lelonek et al., 2018) or alarm (Downes et al., 2009).

Most significantly, there are no specialized teams in the literature dedicated to specifically managing severe behavior for hospital patients with ASD. Recent research found that the third most common diagnosis or presenting concern associated with the dispatch of behavioral emergency teams in one inpatient pediatric hospital was ASD, with other leading diagnoses or concerns including ADHD, anxiety, depression, and suicidal ideation (Derscheid & Arnetz, 2020). The context surrounding severe behavior in patients with ASD may be vastly different (e.g., sensory sensitivities, routine preferences, challenges communicating specific needs; APA, 2022) compared to those with psychiatric concerns; thus, hospital providers’ response to severe behavior should vary across patient populations. However, preliminary data collected by the PI across hospitals in New Jersey, Pennsylvania, and Delaware did not detect teams or response personnel

specifically designed for patients with ASD. Even more concerning, 45% of all hospitals in this geographic region reported no available BRRT (Salvatore et al., n.d.). These findings are problematic given the increased prevalence of ASD nationwide, with higher prevalence estimates in New Jersey (i.e., 1 in 29; Maenner et al., 2023), and the high co-occurrence of severe behavior in patients with ASD (Steenfeldt-Kristensen et al., 2020). Prevalence estimates within this geographic area highlight the critical need for hospital providers to be prepared to treat patients with ASD and severe behavior.

The literature consistently documents deficits in physician knowledge and confidence in treating patients with ASD (Golnik et al., 2009; Oskoui & Wolfson, 2012; Zerbo et al., 2015). Healthcare providers across disciplines, including family and internal medicine, adult mental health, and obstetrics/gynecology, reported poor or fair knowledge of ASD, and that they lacked a sufficient skillset to adequately treat this patient population (Zerbo et al., 2015). Neurologists have also reported less comfort treating adult patients with ASD than adults with other neurological disorders (Oskoui & Wolfson, 2012). Within providers treating children with ASD, pediatric and family physicians rated their competency treating children with ASD as lower than treating those with other neurodevelopmental disorders (Golnik et al., 2009). Gaps in physician knowledge, competency, and confidence in treating patients with ASD may result in increased reliance on restraint and limited safety and effectiveness in treating these patients (Gabriels et al., 2012).

Within the field of applied behavior analysis, functional analysis (FA) is the gold standard approach to determine the maintaining environmental consequence of severe behavior (i.e., the function). Functional behavioral assessment methodology is an

umbrella term for indirect and direct assessments that aim to identify the function of severe behavior, which can ultimately be used to inform individualized treatment (Newcomb & Hagopian, 2018). Rating scales, such as the Questions about Behavioral Function (QABF; Paclawskyj et al., 2000) and Motivation Assessment Scale (MAS; Durand & Crimmins 1988) are used across contexts (e.g., home, school, residential) to gather information from natural change agents (e.g., parents, teachers, direct support professionals) to identify hypothesized function(s). Subsequent direct assessment, such as documenting environmental antecedents and consequences, and experimental analyses, such as FAs, are often conducted to identify function (Oliver et al., 2015). Common functions of severe behavior include access to attention, escape from aversive tasks or stimuli, access to or escape from sensory stimulation, access to tangible items, and routine restoration (Beavers et al., 2013; Hagopian et al., 2007; Iwata et al., 1982/1994).

Function-based treatments are documented as most effective in treating severe behavior compared to other treatment modalities (Campbell, 2003; Heyvaert et al., 2014). The feasibility of physicians implementing function-based treatments when responding to hospital patients' severe behavior has not yet been explored. Identifying the function of a patient's behavior can drastically alter the physician's course of treatment. For example, if a patient is engaging in severe head-banging each time the magnetic resonance imaging machine is taking an image because it results in escape from the aversive noise produced by the machine, then the technician could proactively provide noise-cancelling headphones. The addition of these headphones may block the noise of the machine, protect the safety of the patient, prevent the use of chemical or mechanical restraint, and result in a more positive technician and patient experience. Physicians and medical

trainees themselves have identified the need for function-based training in their medical curriculum (Salvatore et al., 2021). Existing measures have focused on assessing multidisciplinary provider, including physician, knowledge of ASD and endorsed stigma (e.g., Autism Stigma and Knowledge Questionnaire [ASK-Q]; Harrison et al., 2017b). Although there is a need to assess behavioral function and incorporate function-based treatment across medical settings, there is no existing measure in the literature to assess provider knowledge of behavioral function. The proposed investigation aims to develop a survey instrument to measure hospital providers' knowledge of behavioral function. A newly developed function-based measure is an important first step in identifying gaps in knowledge and developing appropriate training programs to better the hospital care received by patients with ASD and severe behavior.

Also lacking in the extant literature is a clear understanding of strategies BRRT personnel use to prevent and manage severe behavior across hospital patients with a variety of diagnoses and presenting concerns. The proposed investigation aims to improve researchers' and practitioners' understanding of BRRT through multidisciplinary focus groups, which could lend itself to potential refinements of these teams to more specifically meet the needs of hospital patients with ASD.

## Chapter 2

### **Study 1: Knowledge of Behavioral Function Survey Development and Assessment of Physician Knowledge of ASD and Behavioral Function**

#### **Method**

To address the absence of a measure in the literature to assess knowledge of behavioral function, a measure assessing hospital provider knowledge of behavioral function was developed by the study team (i.e., author and mentor) using an iterative development process. The measure was then administered to a sample of physicians and medical trainees.

#### ***Measure Development***

The current study used the methodology outlined by Love et al. (2020) to inform measure development. Love and colleagues developed a measure of police officer self-efficacy for working with individuals with ASD using a systematic process of item development and review by experts in related fields. The instrument development process involved (1) Stage 1: Item writing; (2) Stage 2: Expert review; and (3) Stage 3: Cognitive interviews. Figure 1 presents the systematic process that was followed across the item development and data analysis phases.

**Stage 1: Item Writing.** A preliminary version of the survey was developed by the study team through (a) a comprehensive review of the survey development literature in related fields and review of existing autism knowledge measures (e.g., ASK-Q, Harrison et al., 2017b; Autism Spectrum Knowledge Scale, Professional Version – Revised, McClain et al., 2019); (b) consideration of common behavioral functions and assessments for identifying behavioral function (e.g., QABF, Paclawskyj et al., 2000; MAS, Durand

& Crimmins 1988); and (c) experiences treating patients with ASD reported by physicians and medical trainees in the literature (e.g., Salvatore et al., 2021). There is little consensus in the ASD knowledge literature regarding the most effective response option for measuring knowledge (Harrison et al., 2017a). Harrison et al. (2017a) found that half of the reviewed ASD knowledge measures used fact-based statements similar to the ASK-Q, which directly influenced the current measure development. Our study team carefully considered the type of response options that would be presented to survey respondents. Response options of True/False/Don't Know were strategically used for fact-based statements in different sections of the measure to provide participants with restricted response options that could be easily scored as correct or incorrect. Additionally, a Don't Know response option, that was scored as incorrect, was presented to participants given that the study team wanted to decipher between incorrect knowledge and perceived gaps in knowledge.

The measure includes the following three sections: (a) behavioral function statements; (b) vignettes; and (c) optional items. In the behavioral function statement and vignette sections, True/False/Don't Know response options were presented to participants. Responses to the fact-based statements in the behavioral function and vignette sections are included in the total knowledge of behavioral function score. Specific descriptors (i.e., “may,” “unlikely,” “almost always,” “only”) are used in each survey item to accurately capture nuanced situations regarding behavioral function. Given that True/False response options may compromise internal consistency and reliability due to restricted response options (Furr, 2011), duplicate survey items with different correct responses and/or minor wording changes were created to assess if

participants consistently responded to similar items across the measure (i.e., Items 13 & 35; 14 & 28 & 31 & 37). We included these duplicate items and calculated internal consistency for the purpose of this study; we discuss whether to retain these duplicate items in future survey iterations. As informed by the literature, brief surveys (1 to 10 items) have psychometric costs (e.g., poor reliability); thus, an adequate number of survey items were created. The initial survey included 55 items. Worthington and Whittaker (2006) indicated that a shorter time frame of 15 to 20 min is optimal for retaining respondent interest and motivation when completing survey measures. The study team determined that completing the current survey with 64 items in 10 to 20 min is feasible.

An optional section of the survey was created to assess attitudes, comfort, and training regarding treating hospital patients with and without ASD who engage in severe behavior. This section initially included five items and is considered a valuable part of the survey given that previous knowledge measures have examined both total knowledge of a particular construct and attitudes/opinions (i.e., stigma subscale, ASK-Q; Harrison et al., 2017b). This section was designed to provide valuable information for supervisors or administrators that can inform training needs of hospital providers. Example statements include, “I feel discouraged when patients engage in severe behavior during their hospital stay” and “I am comfortable recommending/placing restraint orders to manage patients with autism who engage in severe behavior.” Likert-Scale response options were selected in this section to allow respondents to express degrees of agreement (Furr, 2011). One limitation of including a greater number of response options (i.e., Likert-Scale) is that there is increased risk of acquiescence bias (i.e., the tendency to endorse all items without



regard for their content). To control for this bias within the Likert-Scale items, survey developers created an equal number of positively and negatively worded items to encourage the respondent to cautiously read and consider the fact-based statements (Savalei & Falk, 2014). Responses to items in this section were not included in the total knowledge of behavioral function score.

Survey item content was informed by a review of measures in related fields or areas, including indirect assessment measures of knowledge of ASD and identification of behavioral function. Existing knowledge measures have largely focused on multidisciplinary provider knowledge of ASD. For instance, the ASK-Q (Harrison et al., 2017b) calculates a total knowledge of ASD score. The ASK-Q assesses knowledge across multiple knowledge subscales (i.e., diagnosis/symptoms, etiology, treatment, stigma) but does not include any items specific to behavioral function. In the field of applied behavior analysis, indirect assessment measures assessing behavioral function, such as the QABF (Paclawskyj et al., 2000) and MAS (Durand & Crimmins 1988) are often provided to caregivers to inform subsequent assessment and treatment. However, these measures are completed about a specific client rather than assessing a provider's knowledge of behavioral function itself. Thus, review of the extant literature identified the need for a newly developed measure specific to knowledge of behavioral function. Common functions of severe behavior were incorporated into the survey, as informed by previous research (Beavers et al., 2013; Jessel et al., 2019). Predominant indirect assessment measures assessing behavioral function were also reviewed to ensure that the newly developed survey items were comprehensive in describing typical environmental variables maintaining severe behavior for individuals with ASD. For example, the QABF

asks respondents to rate how often an individual engages in target behaviors under a variety of environmental circumstances. The item “Engages in the behavior because he/she is in pain” was incorporated into the survey as a potential situational variable that may be applicable to a hospital setting. Further, qualitative information in the literature about physicians’ perceptions of the reason severe behavior occurs in hospital patients with ASD was also used to inform survey content. For example, a physician in Salvatore et al. (2021) indicated that “Patients with ASD engage in severe behavior to maintain inner peace”; this language was directly reflected in a survey item representing a false statement regarding behavioral function given that this statement relies on mentalistic explanations.

**Stage 2: Expert Reviews.** The aim of the second phase of the item development process was to gather feedback from experts in related fields to inform survey development (DeVillis & Thorpe, 2022). Research has indicated that a minimum of three expert reviewers should participate per group and they should share similar demographics with the end survey user or work as a professional in a related field (Rubio et al., 2003). Prior to expert reviews, approval from the University’s Institutional Review Board was obtained. Expert reviewers were provided with an electronic copy of the survey measure and asked to provide input related to survey content, survey organization, and survey item wording. In the following order, the survey was reviewed by a sample of five professionals in each of the following categories: (a) board certified behavior analyst (BCBA) experts in behavioral function; (b) behavior technicians who have specific experience with individuals with ASD and with severe behavior, (c) psychology experts with specialized ASD training; (d) individuals with ASD and/or their caregivers; and (e)

physicians or medical trainees. Individual feedback was directly shared with the survey developers via email, resulting in subsequent item revision, addition, or re-organization. See Figure 1 for a visual of the expert review process. Expert reviewers were located across all major geographic regions of the United States. Participant recruitment information for each phase of expert review is described in the corresponding sections below. After initial survey input was collected from all experts in one group, revisions to the survey were made based on the feedback provided. The study team then shared a description of considerations and changes made based on the group's feedback along with the revised survey. Experts in that group were again asked to review the survey measure and provide additional feedback. Consensus was determined when no experts in a group requested further survey item modifications or additions. Once the feedback loop was completed for a group of expert reviewers, the survey measure was sent to the next group of expert reviewers such that revisions were cumulative with the final group of reviewers representing the target end users. See Table A1 for all survey revisions at each phase by revision type (e.g., item additions, clarity improvements, and organization changes).

In Phase 1, BCBAs were identified by the survey developers through professional connections with BCBAs nationwide who have expertise assessing behavioral function in hospital or intensive clinical settings. Eight knowledge of behavioral function survey items were revised for clarity and/or to present more accessible or physician-friendly information (e.g., revising item 12 from “something to do” to “something to *keep them occupied*”; revising item 16 to add detail, “Patients with autism almost always engage in severe behavior because they cannot help it *or control their behavior*”). A total of six

items were added to the survey, including incorporating additional questions to the optional Likert-Scale questions section (i.e., item 63, “I feel discouraged when patients engage in severe behavior during their hospital stay” and item 64, “I recommend/place restraint orders when myself and/or my team feels unsafe or uncomfortable managing hospital patients’ severe behavior.”) and adding open-ended response items to vignette questions (i.e., “What do you think is causing the severe behavior?”). Based on expert feedback, the open-ended question for each vignette was modified to require a response in the online administration prior to accessing remaining survey items to elicit respondents’ perspective on behavioral function without the leading influence of subsequent True/False questions. Thirteen vignette survey items were revised for clarity to ask participants similar but differently worded questions for each different vignette scenario to avoid a predictable response pattern and potential over-penalization should the participant incorrectly respond to the same question across each vignette. For instance, three similar survey items are included, each pertaining to a different vignette, (a) “There is no way to evaluate why this patient’s severe behavior is occurring”; (b) “There are ways to evaluate why this patient’s severe behavior is occurring”; and (c) “It is possible to identify why this patient’s severe behavior is occurring.” The four optional Likert-Scale survey items were re-ordered to appear after the knowledge of behavioral function items as they do not factor into the total knowledge score and are outside of the scope of assessing knowledge of behavioral function.

In Phase 2, behavior technicians were identified by the study team to include those who have experience with individuals with ASD and with severe behavior. Behavior technicians were recruited from facilities and programs that specifically focus

on the assessment and treatment of severe behavior in individuals with ASD. A total of 35 knowledge of behavioral function survey items were revised for clarity (e.g., revising item 11 for clarity from “Patients with autism’s severe behavior is less likely to be repeated at future hospital visits with *similar circumstances*.” to “Patients with autism’s severe behavior is less likely to occur again when they *return to the hospital and encounter a similar scenario*.”) and to present more accessible information (e.g., revising “cannot” to “can’t”).

In Phase 3, experts in the field of psychology with specialized ASD training were identified by the survey developers through professional connections with academic institutions and treatment facilities. Specialized ASD training includes applied research specific to individuals with ASD and clinical experience assessing and treating individuals with ASD and their families. Two vignette survey items were revised for clarity and/or to present more accessible or physician-friendly information (e.g., revising item 45 from “The patients’ severe behavior will continue with no predictable pattern” to “The hospital staff *cannot predict* when severe behavior will *occur during future medical appointments*”; revising item 51 from “The patients’ severe behavior is likely to continue with a predictable pattern at future medical appointments” to “The patients’ severe behavior will *occur again during future medical appointments*”). One Likert-Scale question was revised for clarity to remove the term “*often*” in an attempt to remove blame and stigma of restraint implementation from the physician (i.e., “I often recommend/place restraint orders when I feel unsafe or uncomfortable managing hospital patients’ severe behavior” to “I recommend/place restraint orders when I feel unsafe or uncomfortable managing hospital patients’ severe behavior”).

In Phase 4, individuals with ASD and/or their caregivers were recruited from specific organizations representing individuals with ASD (e.g., university Centers for Neurodiversity, autism caregiver support groups) nationwide. To be eligible for expert review, participants needed to (a) have a diagnosis of ASD or be a primary caregiver of an individual with an ASD diagnosis and (b) have experienced challenging behavior while receiving medical care or have observed their child engage in challenging behavior while receiving medical care. Eleven knowledge of behavioral function survey items were revised for clarity (e.g., changing item 18 qualifier from “only” to “always”; adding “may” as a qualifier to item 55) and to promote alignment with behaviorally-based terminology (e.g., “Patients with autism may engage in severe behavior because it is something to keep them occupied.” to “Patients with autism may engage in severe behavior because of the sensation it produces when they’re in an environment that lacks things they find engaging.”). Two items with the initial phrasing “Severe behavior in patients with autism...” were re-ordered to follow items with identical phrasing.

In Phase 5, physicians and medical trainees were recruited through medical program leadership and hospital administrators at two medical schools and affiliated hospitals in a densely populated Northeastern state. Physicians and medical trainees from various target hospital departments were recruited to ensure that multiple perspectives were solicited. This group of expert reviewers was specifically included to ensure that the survey content accurately portrays hospital patients with ASD and is relevant for the intended target users. Four knowledge of behavioral function survey items were revised for clarity (e.g., “Patients with autism only engage in severe behavior when someone is in the room” to “Patients with autism only engage in severe behavior when in the presence

of others”; revising a qualifier from “may” to “unlikely”). After the subsequent Stage 3 was completed, this group of expert reviewers completed a final review of the revised survey measure.

**Stage 3: Cognitive Interviews.** The goal of this phase was to ensure that items are interpreted correctly and to understand participant response processes (American Educational Research Association et al., 2014). Cognitive interviewing is a valuable technique used by survey developers to gain a comprehensive understanding of how participants may respond and to gain insight into their thought processes which can ultimately be used to inform survey development and promote content validity (Peterson et al., 2017). Physicians and medical trainees were recruited via identical recruitment procedures as described in the above expert review process (Stage 2; Phase 5). Five additional participants were selected for cognitive interviews as they represent the intended survey end user. Physicians were privy to the measure’s intended purpose in assessing knowledge of behavioral function such that the study team could gather an understanding of physicians’ current function-based knowledge, thought processes when responding to each question, and consideration of the relevance of each question to their practice.

Following methodology described in the published literature (Love et al., 2020; Peterson et al., 2017; Willis, 2013), cognitive interviews were completed. The author conducted cognitive interviews via WebEx call and followed a standardized verbal script with scripted probing questions. All interview probing questions were reviewed by the study team to ensure appropriate line of questioning, and all suggested modifications to improve interview probing questions were addressed. The author was trained to conduct

cognitive interviews through formal didactic training and two mock cognitive interview exercises. Physicians were asked to complete the measure while on video call and describe their thought processes and responses as they proceeded through each item. Interview responses were automatically transcribed using the WebEx recording feature and reviewed for clarity prior to their interpretation for future survey development.

### ***Measure Administration***

Following the completion of measure development, the Knowledge of Behavioral Function (KoBF) survey was administered electronically to a sample of medical trainees and physicians nationwide to measure knowledge of behavioral function.

### ***Participants***

Per G\*Power power analysis calculations conducted *a priori* with a significance criterion of  $\alpha = .05$ ,  $f = 0.05$ , and power = .95 (Faul et al., 2007), a sample size of up to 138 participants was needed (one-way ANOVA,  $n = 128$ ; linear regression,  $n = 89$ ; Pearson correlation,  $n = 138$ ). As such, we obtained a total of 150 complete responses from our target groups. Participants completed (1) the KoBF survey measuring knowledge of behavioral function developed by the study team; and (2) the ASK-Q (Harrison et al., 2017b) to measure knowledge of ASD.

Demographic information was collected through multiple choice questions (e.g., “Select your credentials”). The greatest percentage of participants were male (56%), White (53%), attending physicians (34%), had M.D. credentials (73%), and had 16+ years of experience (38%). See Table A2 for participant demographics.



### ***Recruitment***

Physicians were recruited via direct emails to medical program leadership and hospital administrators requesting that recruitment information be shared with eligible individuals. Recruitment materials were worded in general terms such that participants did not seek out knowledge of behavioral function prior to survey participation and to prevent oversampling of those with prior knowledge of ASD and behavioral function. For instance, recruitment materials included statements such as, “We are gathering information that will help improve services provided to patients with ASD” rather than “We are assessing your knowledge of ASD and behavioral function.”

### ***Procedure***

Informed consent was obtained at the start of the survey prior to the display of questions. Participants completed the KoBF and ASK-Q using the Qualtrics® survey platform (2021) and responses were recorded anonymously. Participants responded to a captcha to verify that they were a human user prior to accessing the surveys. Participants received a single link that included both survey measures so that they could complete the assessments at a convenient time, across multiple days, if needed. Following completion of both measures, participants were entered into a random drawing for a \$75 electronic gift card.

**Knowledge of Behavioral Function Survey.** Following demographic items, participants selected the topographies of behavior they considered to be severe behavior from a list. The survey itself includes three sections: (a) 27 fact-based questions; (b) four vignettes with 20 fact-based questions and four open-ended questions; and (c) five optional Likert-Scale questions. All fact-based questions had True/False/Don’t Know

response options; with correct answers including 12 true responses and 15 false responses, all loading into a total knowledge score. Open-ended responses to vignettes were scored as correct or incorrect using predetermined criteria of the correct behavioral function; however, these items did not load into the total knowledge score. Optional Likert-Scale items were on a 5-point scale, ranging from Strongly Agree to Strongly Disagree and were not scored as correct or incorrect. With outliers removed (i.e., less than 5 min completion time and no more than 2 hr completion time, median survey duration was 14 min and mean survey duration was 18 min (range, 5 min to 2 hr). See Appendix C for the KoBF survey measure.

**Autism Stigma and Knowledge Questionnaire.** Participants' knowledge of the core features of ASD was measured via the ASK-Q (Harrison et al., 2017b). Responses to the ASK-Q were collected after the KoBF survey as this is a secondary aim of the proposed investigation. The 49-item survey yields a total knowledge score and the following subscale scores: (a) diagnosis/symptoms, (b) etiology, (c) treatment, and (d) stigma. The seven stigma items are reverse scored as either endorsing stigma (3-7) or endorsing minimal to no stigma (0-2); items in the stigma subscale do not load into the total knowledge score. This measure was selected due to its strong psychometric properties, including high internal consistency (Cronbach's  $\alpha = 0.88$ ) and test-retest reliability across subscales (range, 0.93 to 0.98; Harrison et al., 2017b). Cross-cultural utility of the ASK-Q was indicated by adequate internal consistency (Cronbach's  $\alpha = 0.72$ ) and high test-retest reliability (Intraclass correlation = 0.86; Harrison et al, 2019).

## ***Data Analysis***

Descriptive statistics (i.e., mean, median, range) were reported for all quantitative study variables (i.e., total and subscale KoBF scores, total and subscale knowledge of ASD scores). The percentage of Don't Know responses was calculated for each participant by dividing the total number of Don't Know responses endorsed on the KoBF by the total number of KoBF items, and descriptive statistics were calculated across participants. The number of participants who responded Don't Know for all response options on the KoBF was also determined. We also calculated the percentage of correct responses across different content categories. See Appendix E for KoBF items grouped by category. Responses patterns to duplicate items were also examined to calculate the percentage of participants who endorsed the same response patterns (i.e., both correct responses, both incorrect responses, both Don't Know responses) across pairs of duplicate items. The following statistical analyses were conducted using SPSS®: (a) one-way ANOVA (i.e., discipline and knowledge of behavioral function) with post-hoc Tukey tests if a significant main effect were detected; (b) linear regression (i.e., years of experience and knowledge of behavioral function); and (c) Pearson correlations (i.e., knowledge of ASD and knowledge of behavioral function).

Open-ended responses (i.e., "What do you think is causing the severe behavior?") for each vignette were thematically analyzed using the constant comparative method of qualitative data analysis (de Casterlé et al., 2020; Glaser & Strauss, 1967) to identify common themes across participants. A codebook including operational definitions of themes identified was created and revised as needed in the event of coding disagreements. Interobserver agreement was determined by a post-baccalaureate research

assistant double-coding 50.67% of open-ended survey responses and comparing codes from the author. Percent agreement was calculated by dividing the total response 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 segment of a participant response and the other coder providing no code). The secondary coder was trained by reviewing and coding a brief sample transcript to ensure coding accuracy of at least 90% three times consecutively with the primary coder. Interobserver agreement was 93.1%. Disagreements that were categorized as commission errors was 32.2% and disagreements that were categorized as omission errors was 43.2%.

Additionally, open-ended responses for each vignette were scored as Correct, Partially Correct, and Incorrect identification of behavioral function. Specific scoring criteria per vignette were created by the study team. The study team scored correct hypothesized function with the following criteria: (a) response indicated the correct environmental consequence that maintains the target behavior (i.e., function), and (b) response did not include any incorrect or internalizing statements. For example, Vignette 1 describes an attention function in which participants must identify the correct environmental consequence (e.g., “patient is getting attention from the nurse”) and not attribute the behavior described to internal causes (e.g., “the patient has autism and is out of control”). The responses scored as Partially Correct include some mention of the correct antecedent variables (e.g., patients wants attention), but fail to mention the consequence that would reinforce and maintain the behavior (e.g., attention provided). Interobserver agreement for correct responses was determined by a BCBA-D-level study

team member double-coding all of open-ended survey responses and comparing codes from the author. Scoring agreement was 99.2%.

## **Results**

### ***Topographies of Severe Behavior***

Most commonly, participants considered self-injury (93%), threatening oneself or others (91%), and aggression (89%) as severe behavior. Participants least often selected noncompliance with medical procedure or exam (11%) and repetitive statements (9%). See Table A3 for the topographies of behavior participants selected as severe behavior.

### ***Knowledge of Behavioral Function***

A total of 232 survey responses were collected. Out of 232 responses, 150 complete survey responses were analyzed. The remaining 82 responses were omitted due to incomplete responses ( $n = 70$ ) and not meeting inclusion criteria (outside of United States,  $n = 11$ ; not a physician or medical trainee,  $n = 1$ ). Participants obtained a mean total score of 31.3 out of 47 ( $SD = 8.8$ ; range, 0 to 44;  $Mdn = 33$ ). In the KoBF statements subscale, participants obtained a mean score of 16.9 out of 27 ( $SD = 5.4$ ; range, 0 to 23;  $Mdn = 18$ ). In the Vignette subscale, participants had a mean score of 14.1 out of 20 ( $SD = 4.3$ ; range, 0 to 19;  $Mdn = 15$ ). The mean percentage of Don't Know responses by participant was 8.65 (range, 0 to 47,  $Mdn = 6$ ). Only one participant indicated Don't Know for all 47 survey items. In the absence of a better metric, we considered a total percent correct of 70% or higher as an acceptable score to mirror the ASK-Q. A total of 56% of participants demonstrated an acceptable score at or above 70%. See Figure 2 for KoBF physician percent correct by subscale. When analyzing correct responses grouped by content category, participants most frequently responded correctly to questions on

positive versus negative reinforcement (87%), whereas the lowest percent correct was in the category of automatic positive reinforcement (42%). See Table A4 for correct responses by category.

Mean inter-item correlation calculations identified item redundancy across both subscales (0.91 Behavioral Function Statements; 0.87 Vignettes). The percentages of participants endorsing the same response patterns for duplicate questions were as follows: (a) items 31 and 37, 33.33%; (b) items 13 and 35, 74%, and (c) items 14 and 28, 79.33%.

### ***Themes by Salience***

Across the four vignette open-ended questions, 39 themes and 33 subthemes were identified. See Appendix D for descriptions of each theme. See Table A5 for frequency and percentage of themes mentioned across vignettes. The top three most salient themes per vignette are described below.

**Vignette 1.** The three most frequent themes that emerged from participant responses from *Vignette 1* (i.e., describing an attention function) included:

***Environment as Contributing Factor (Theme 1).*** The most salient theme reported by participants was that particular aspects of the environment or the environment itself was causing patient severe behavior. Subthemes included: (a) a new and uncertain environment or routine (e.g., “unfamiliar place,” “being in an unusual situation”); (b) uncomfortable environment (e.g., “being in an uncomfortable setting,” “discomfort with the setting of the exam room/hospital setting”); (c) hospital environment/setting in general (e.g., “hospital environment,” “being in that room”); (d) overstimulating environment (e.g., “the patient may be overstimulated in the environment”); (e) environmental demands (e.g., “the patient may not respond well to verbal reprimand,”

“being told what to do”); and (f) small or enclosed spaces (e.g., “small space,” “being trapped”).

***Internal Stimuli as Contributing Factor (Theme 2).*** Participants reported that internal stimuli are causing patient severe behavior. Subthemes included: (a) the patient has different feelings (e.g., “the patient is nervous,” “anxiety, stress”), (b) the patient is uncomfortable (e.g., “the patient is uncomfortable,” “discomfort”), and (c) the patient is in pain (e.g., “pain”).

***Patient Seeking Attention (Theme 3).*** The third most salient theme reported by participants indicated that the patient is seeking attention from nurses and other staff. Subthemes included: (a) the patient wants attention (e.g., “desire for attention,” “trying to gain attention”), and (b) the patient gets attention (e.g., “verbal attention received for behavior,” “possibly attention-maintained if staff give attention to the behavior”). Of note, Theme 3; Subtheme b is the correct response as it refers to the consequence of obtaining attention.

**Vignette 2.** The three most frequent themes that emerged from participant responses from *Vignette 2* (i.e., describing a tangible function) included:

***Stethoscope as Contributing Factor (Theme 1).*** The most salient theme reported by physicians indicated that the stethoscope contributes to patient severe behavior. Subthemes included: (a) the behavior results in access to the stethoscope (e.g., “the patient may remember getting to hold the stethoscope at the prior appointment after exhibiting severe behavior”); (b) the patient wants to hold, get, or touch the stethoscope (e.g., “desire to hold stethoscope,” “patient would like the stethoscope”); (c) the patient uses the stethoscope to soothe or feel pleasure (e.g., “holding stethoscope seems to soothe

the patient”); (d) the healthcare provider removed the stethoscope (e.g., “he didn’t like when the doctor took away the stethoscope”); and (e) the patient is uncomfortable with the presence of the stethoscope (e.g., “is uncomfortable with the stethoscope,” “feeling unsettled by stethoscope”). Of note, Theme 1; Subtheme 1 is correct as it mentions the consequence of accessing the stethoscope.

***Unknown Contributor or Lack of Training (Theme 2).*** The second most salient theme reported by participants is that they did not know why the severe behavior was occurring or indicated a lack of training (e.g., “unknown,” “I’m not sure,” “Really don’t know- general clinical training in medical school does not give specific-enough expertise for these scenarios”).

***Physician and Patient Conflict as Contributing Factor (Theme 3).*** Finally, participants indicated that a power differential or discordance between the provider and patient was the reason severe behavior occurred. Subthemes included: (a) problematic responses from healthcare providers (e.g., “Discomfort brought from a past interaction with a physician”); (b) the patient is angry with the physician (e.g., “anger towards the physician”); (c) disagreement between the physician and patient (e.g., “the disagreement impact from the physician on the patient”); (d) the patient wants something because it belongs to the provider (e.g., “desire to hold something of the physician’s”); (e) the physician is asking the patient to do something they don’t want to do (i.e., “Physician asserting demand and not giving the patient something they want”); and (f) the patient is afraid of the doctor (i.e., “afraid of doc”).

**Vignette 3.** The three most frequent themes that emerged from participant responses from *Vignette 3* (i.e., describing an escape from physical touch scenario) included:



***Escape as Contributing Factor (Theme 1).*** The most salient theme reported by physicians was that the patient is attempting to escape. Subthemes included: (a) the patient is uncomfortable with physical touch and/or is attempting to escape physical touch (e.g., “displeasure for physical touch,” “discomfort with being touched”); (b) severe behavior results in the provider terminating or avoiding physical touch (e.g., “patient does not seem to respond well to touch and is not touched after these behaviors,” “patient does not like being touched and knows that if they spit and push the healthcare worker, that person will ultimately stop in next encounter”); and (c) the patient is attempting to escape the appointment or scenario (e.g., “patient believes that spitting causes staff to back away,” “lack of desire to be at appointment”). In this scenario, Theme 1, Subtheme b is the correct response because it mentions the consequence of escaping physical touch.

***Unknown Contributor or Lack of Training (Theme 2).*** Physicians reported that they did not know why the severe behavior was occurring or indicated a lack of training (e.g., “unknown,” “I’m not sure,” “Again don’t know with confidence due to lack of specific training for these kind of scenarios”).

***Patient Feelings as Contributing Factor (Theme 3).*** The third most salient theme reported by physicians concerned a broad range of patient feelings, including anxiety, fear, anger, stress, disapproval, and pain (e.g., “Anxiety, fear, stress,” “Fear, discomfort, stress, anxiety”).

**Vignette 4.** The three most frequent themes that emerged from participant responses from *Vignette 4* (i.e., describing an escape from aversive procedure scenario) included:

***MRI as Contributing Factor (Theme 1).*** The most salient theme reported by physicians in Vignette 4 was that the MRI caused the patient severe behavior. Subthemes included: (a) the patient is afraid, surprised, or anxious about the MRI (e.g., “They are afraid of the MRI,” “anxiety over MRI”); (b) the patient is attempting to escape the MRI (e.g., “desire to not be in the MRI,” “desire to avoid unwanted procedures”); (c) the patient escaped or avoided the procedure (e.g., “He is learning that his negative behavior helps him avoid things he doesn’t like,” “The patient seems to have learned that to avoid certain types of care, the patient can engage in severe behaviors”); and (d) the patient is experiencing overstimulation from the noise of the machine (e.g., “overstimulation via noises from MRI”). In this vignette, Theme 1, Subtheme c is the correct response because it describes the patient escaping the aversive procedure.

***Patient Feelings as Contributing Factor (Theme 2).*** The second most salient theme reported by physicians concerned a broad range of patient feelings, including discomfort, anxiety, fear, anger, stress, panic, and frustration (e.g., “the patient’s pain or illness,” “anxiety and fear”).

***Unknown Contributor or Lack of Training (Theme 3).*** The third most salient theme reported by physicians indicated that they did not know why the behavior was occurring or indicated a lack of training (e.g., “don’t know,” “hard to say,” “not too sure given lack of specific training for these scenarios”).

Across the four open-ended vignette questions, 11.44% of responses were scored as correct, with the highest percentage correct for Vignette 3 (14.67%). See Table A6 for percent correct and percent partially correct scores for each open-ended vignette question. See Figure 3 for percent correct and partially correct scores for each vignette. See Table

A7 for examples of scored correct responses across open-ended vignette items.

Interobserver agreement for correct responses was determined by a BCBA-D-level study team member double-coding all open-ended survey responses and comparing codes from the author. Scoring agreement was 99.17%.

The most frequently indicated direction of Likert-Scale responses is reported per optional item across participants. See Table A8 for percentages of each response option per Likert-Scale item. For the item, “I feel discouraged when patients engage in severe behavior during their hospital stay,” 67% of participants responded that they Agree or Somewhat Agree. For item, “I recommend/place restraint orders when myself and/or my team feels unsafe or uncomfortable managing hospital patients’ severe behavior,” 65% of participants reported that they Agree or Somewhat Agree with the statement. For the item, “I am comfortable using restraint either myself or with a team to manage patients with autism’s severe behavior,” 43% of participants reported that they Disagree, whereas 24% reported Somewhat agree. For the item, “I am comfortable recommending/placing restraint orders to manage patients with autism who engage in severe behavior,” 33% of participants reported Disagree followed by 28% reporting Somewhat Agree. For item, “I currently receive sufficient training to manage patients with autism who engage in severe behavior,” 70% of participants reported that they Disagree or Strongly Disagree.

### ***Autism Stigma and Knowledge***

Survey responses on the ASK-Q were collected from 125 of 150 participants. A total of 112 out of 125 participants (91.1%) demonstrated adequate knowledge of autism across all three subscales with a total mean score of 38.8 out of 48 ( $SD = 5.8$ ; range, 17 to 47). For the diagnosis/symptoms subscale, participants obtained a mean score of 14.5 out

of 18 ( $SD = 2.5$ ; range, 7 to 18). For the etiology subscale, participants obtained a mean score of 12.4 out of 16 ( $SD = 2.7$ ; range, 6 to 16). For the treatment subscale, participants obtained a mean score of 11.9 out of 14 ( $SD = 1.9$ ; range, 5 to 14). Out of the seven stigma items, none of the participants reported instances of stigma. See Figure 4 for ASK-Q percent correct scores by subscale. The value for Cronbach's alpha for the survey was  $\alpha = .875$ , suggesting high internal consistency.

### ***Quantitative Analyses***

The significance level was set a priori at  $\alpha = .05$  for all statistical tests. The skewness of all KoBF items was -1.50 which indicates negatively skewed data within the normal limits ( $\pm 2$ ) of a univariate distribution (George & Mallery, 2019). However, the kurtosis value of 2.29 was outside of normal limits, indicating a heavily peaked distribution. Analysis of individual participant data indicated three outliers with extremely low scores (e.g., KoBF total score = 0). As such, these three participants' data were removed from subsequent analyses. With these data removed, skewness and kurtosis values were both within normal limits (i.e., -1.33 and 1.77, respectively). For the KoBF, a one-way ANOVA was calculated to evaluate KoBF total scores based on the categorical value of years of experience,  $F(4, 145) = 1.994, p = 0.98$ . Given that a statistically significant main effect was not found, post-hoc tests were not conducted. There was a statistically significant difference between discipline on knowledge of behavioral function as determined by a one-way ANOVA ( $F(8, 140) = 2.11, p = .04$ ). A statistically significant main effect was found in post-hoc tests between psychiatry and other/not specified disciplines ( $p = 0.013$ ), with higher KoBF scores found in the psychiatry group.

For the ASK-Q, the skewness was -1.31, which indicates negatively skewed data within normal limits. The kurtosis was 1.83, which indicates slightly peaked data within normal limits. There was not a statistically significant difference between years of experience on ASK-Q scores as determined by a one-way ANOVA ( $F(3, 116) = 1.469, p = .227$ ); therefore, post-hoc tests were not conducted. There was a statistically significant difference between discipline on ASK-Q scores as determined by a one-way ANOVA ( $F(8, 111) = 2.252, p = .029$ ). A statistically significant main effect was found in post-hoc tests between radiology and pediatrics ( $p = .037$ ), with higher KoBF scores found in the pediatrics group.

To assess the linear relationship between knowledge of autism and knowledge of behavioral function, a Pearson correlation coefficient was computed between ASK-Q total scores and KoBF total scores. A nonsignificant correlation was detected between the two measures ( $r(145) = -.103, p = 0.25$ ).

## **Discussion**

This study provides important information about physician and medical trainees' knowledge of ASD and knowledge of behavioral function. Study aims included: (1) to develop a survey assessing multidisciplinary provider knowledge of behavioral function; and (2) to quantify physician and medical trainee knowledge of behavioral function and ASD. A previous qualitative investigation suggested that medical trainees and physicians demonstrate poor understanding of behavioral function (Salvatore et al., 2021). To our knowledge, the KoBF measure developed in this study is the first survey measure intended to assess knowledge of behavioral function. This study extended the literature by quantifying medical trainee and physician knowledge of behavioral function with the

long-term goal of using this information to guide improvements to the quality of hospital care delivered to autistic patients.

Most significantly, this study concluded that medical trainees and physicians lack a comprehensive understanding of behavioral function. On average, participants obtained a total score of 33.3 of 47 on the KoBF survey (66.50% correct) with less than 60% of participants demonstrating an “acceptable” score (i.e., 70% or greater), using 70% correct as a measure of acceptable knowledge, based on the ASK-Q in the extant literature (Harrison et al., 2017b). These results indicate a need to improve medical trainee and physician knowledge of behavioral function. Despite low knowledge of behavioral function, this study found that participants had adequate knowledge of ASD and lacked stigma related to autistic individuals. On average, participants obtained a total score of 38.8 of 48 on the ASK-Q survey (80.90% correct). A total of 91.10% of participants demonstrated an adequate score on the ASK-Q, which further indicates that the majority of medical trainees and physicians sampled have a strong understanding of ASD. This study is consistent with published research demonstrating that physicians have adequate knowledge of ASD (Salvatore et al., 2021). Relatedly, when asked to identify what they considered severe behavior from a list of common topographies, it is promising that few physicians suggested that repetitive motor movements, repetitive statements, and noncompliance were considered severe behavior. Repetitive behaviors are related to core features of ASD and all three topographies do not present a risk to oneself or others and should not be treated as warranting immediate intervention. However, having foundational knowledge about ASD does not lead to a strong understanding of behavioral function.

Knowledge of behavioral function is a nuanced area which may be explicitly targeted in future medical curriculum and continuing education as many participants indicated in open-ended responses and optional Likert-scale items that they receive insufficient training in autism and severe behavior. Further, across the KoBF, participants selected the Don't Know response for an average of 18% of items, supporting their lack of training and experience in this area. In a recent systematic review of 16 studies examining features and educational outcomes of existing postgraduate medical education curricula, Adirim et al. (2021) discussed the need for competency-based training targeting the growing population of individuals with intellectual and developmental disabilities. Their study findings indicated that current medical training is satisfactory in changing post-graduate medical trainee objective knowledge, skills, and attitudes; however, current training promotes low levels of change in practice. Interestingly, on the KoBF open-ended items, when participants were presented with scenarios that may be similar to those they encounter in practice, only about 11% of participant responses correctly identified the hypothesized function of the patient's severe behavior. The current study expands on the importance of improved and specialized instruction that focuses on realistic scenarios and practical outcomes to better address the needs of autistic hospital patients.

Improvements in medical trainee and physician knowledge of behavioral function offer many advantages for the patients and physicians alike. First, training specifically designed to build knowledge of behavioral function may assist physicians in broadly understanding the potential environmental responses that maintain patient severe behavior. As a result, physicians may be able to more effectively and quickly treat

autistic patients who engage in severe behavior. Historically, medical providers have noted that autistic patients are more time-consuming and resource-intensive compared to neurotypical patients (Mazurek et al., 2020). Specialized training in behavioral function can improve practical skills leading to a quicker and more time-effective response to challenging behaviors. For instance, physicians may be able to consider the environmental variables that may contribute to patient severe behavior in the moment and use that information to guide their response in a compassionate manner, without reinforcing the challenging behavior. Training in behavioral function may also improve medical trainee and physician understanding of antecedent-based intervention. Given the documented effectiveness of autism-specific care plans in serving autistic hospital patients (Broder-Fingert et al., 2015), there may be utility in adopting these plans across hospitals to promote the use of function-based strategies. For instance, physicians with a better understanding of behavioral function may implement antecedent-based strategies in line with behavioral function such as proactively allowing the use of a preferred tangible item during scheduled examinations or procedures. To achieve the greater goal of physicians implementing function-based strategies, specialized training efforts are required.

A greater understanding of function and function-based interventions may result in providers decreasing their reliance on restraint when responding to autistic hospital patients. In the Likert-Scale section, although medical trainees and physicians suggested that they are largely not comfortable with recommending restraint, the majority endorsed the use of restraint when managing patient unsafe and interfering behaviors. Previous studies indicated that autistic patients experience an increased risk of restraint following



the occurrence of severe behavior (O'Donoghue et al., 2020), and restraint can lead to serious risk for hallucinations, re-traumatization, injuries, or death (Perers et al., 2021). These findings are consistent with qualitative research that suggests physicians are uncomfortable implementing restraint; however, they continue to use restraint when faced with emergent severe behavior (Salvatore et al., 2021). Taken together, it is critical for physicians to have a baseline knowledge and understanding of behavioral function but, most importantly, to use this knowledge to safely and effectively respond to patient severe behavior.

Relatedly, training targeting behavioral function is needed to promote high-quality neurodiversity-affirming care for autistic patients. In our study, many medical trainees and physicians across open-ended vignette questions indicated that autism itself is the sole contributor to the patient's severe behavior. One notable participant response stated, "Patients with autism focus on one task and become violent when distracted." Unfortunately, these stigmatizing statements are not novel as many studies have documented healthcare providers' negative and inaccurate perceptions of autistic patients. For instance, when discussing autistic patients, healthcare providers have described these patients as more "threatening," "dangerous," and "difficult" (e.g., Gardner et al., 2016; Salvatore et al., 2021). Not only do these perceptions lack consideration of the environmental variables contributing to severe behavior but, most importantly, they indicate a lack compassion towards patients with autism. If healthcare providers approach patients with autism assuming they are "violent" or "dangerous," that may impact the way that they interact with the patients and deliver medical care. Further, there is a wide variety of literature describing the experiences of autistic individuals in accessing

medical care. In a study examining personal experiences in accessing medical care, autistic adults with higher healthcare needs reported greater dissatisfaction with medical care received compared to those with fewer healthcare needs (Vogan et al., 2017). In addition to attributing severe behavior to characteristics of autism, in response to the open-ended vignette questions, participants described other mental health concerns or risk factors including: “sociopathy,” “depression, anxiety, ADHD,” “neurocognitive impairment,” “sexual abuse in the past,” and “frontotemporal dementia.” Attributing severe behavior to mental health concerns or making assumptions about past experiences that were not described in the scenarios further highlights how medical trainees and physicians lack an understanding of how environmental variables may impact the care they provide. With specialized training about behavioral function, physicians may be able to understand the many reasons why severe behavior may occur and view it as less of a threat or inconvenience in their daily practice when they are more empowered with strategies to prevent and respond to these behaviors.

There are many other limitations to viewing the patient’s ASD diagnosis or other mental health concern as a primary explanation for severe behavior. Regarding autism, autistic individuals present differently based on the situation they are in and their unique presentation of core features of ASD. Per the DSM-5-TR diagnostic criteria (APA, 2022), autistic patients may have unique sensory and routine preferences that are not readily compatible with standard hospital environments. Further, the hypothesized function of one autistic patient’s severe behavior will not be identical to the hypothesized function of severe behavior for another autistic patient. In future training, it is essential to teach healthcare providers that it is not the ASD or other mental health diagnosis in isolation

that “causes” the severe behavior; rather, the environmental variables and unique individual characteristics must be examined in combination when interacting with hospital patients who engage in severe behavior.

From our analysis of correct responses by category of behavioral function, areas of greatest identified need include a better understanding of (a) automatic reinforcement, wherein the participant’s behavior itself produces access to something desirable or escape from something unpleasant, independent of others; (b) socially-mediated negative reinforcement, wherein the behavior results in someone else in the environment facilitating escape from or avoidance of something unpleasant; and (c) reinforcement maintains behavior, meaning that behavior continues to occur because of the environmental consequences that follow. These areas are important to incorporate into hospital training such that providers recognize that their responses to severe behavior may maintain those behaviors over time and that individuals may engage in certain behaviors (e.g., self-injury), because they directly produce a sensory consequence, such as a preferred sensation or removal of an unpleasant stimulus in the environment.

Hospital administrators and those responsible for medical training may recognize the utility and necessity in improving knowledge of behavioral function. For example, those responsible for medical training may embed training in behavioral function early in a physician’s career, such as targeting understanding of types of severe behavior and potential environmental triggers that evoke and consequences that maintain severe behavior. In targeting current medical trainees’ and physicians’ knowledge, hospital administrators may attempt to combat negative evaluations of autistic patients to promote safe and equitable care through improved training efforts. Fortunately, there are many

experts that can assist in creating robust training programs. Results of this study suggest that psychiatrists may have more knowledge when compared to physicians of an unspecified or nontraditional discipline. However, given that there were minimal detected differences in knowledge of behavioral function by discipline, physicians across specialties would likely benefit from such training. More broadly, continuing education would be beneficial for all hospital physicians in practice as many have not received adequate function-based knowledge, and, per our analysis of years of experience on total knowledge of behavioral function, many do not appear to develop this knowledge through their practice over time. Experts in applied behavior analysis, as well as autistic individuals and their caregivers would be ideal candidates for creating a strong and meaningful training that can both compassionately and effectively respond to autistic patients who engage in severe behavior. With the rise of simulation-based training and the documented effectiveness of this training style (Mitchell et al., 2020), hospitals may consider combining simulation-based training programs with a behaviorally based curriculum targeting knowledge of behavioral function. As a whole, there are various existing training formats which can be adopted in targeting physician knowledge of behavioral function.

There are several limitations to this study. First, the KoBF survey itself consists of 52 total items which can result in a lengthy administration time, particularly if participants provide thorough responses to the four open-ended items. Out of 232 total responses, less than 65% of participants completed the entire survey measure and met inclusion criteria. Second, because the survey was administered electronically, there is a possibility that participants looked up information on the internet to assist them in

answering survey items; however, as behavioral function is a nuanced knowledge area, it would have been difficult for participants to locate answers. Given the low median completion time, it appears that most included participants progressed through the survey within a reasonable time period. Finally, the KoBF measures physician knowledge of behavioral function rather than their responses to severe behavior. It must be noted that low knowledge of behavioral function may not correlate with a poor response to severe behavior. Future research may consider investigating the relationship between KoBF total scores and measurable behavioral responses.

There are also limitations to our sample. Although our sample is largely representative of the current physician workforce reported by the Association of American Medical Colleges (2019), specific diverse groups (e.g., Black or African American physicians) were less represented in this study than in the population. Our sample was also largely overrepresented by medical trainees and physicians in the Northeast geographic region. Future research may explore differences in knowledge of autism and behavioral function between geographic regions, hospital type, and training level to guide future training.

The broader goal of this study was to develop and disseminate a measure that quantifies knowledge of behavioral function across multidisciplinary hospital providers. One strength of this study was the user-centered iterative development process that was used to develop the KoBF. This process involved a significant time investment by both the study team and multidisciplinary professionals which made for a stronger measure. Most significantly, the study team also included the perspectives of autistic individuals and their caregivers in the survey construction process to ensure that the measure best

reflects the experiences of a diverse group of autistic individuals and those in caregiving roles. Although thorough revisions were made to the survey guided by different expert perspectives, future research is needed to validate the KoBF. Future research should further evaluate psychometric properties of the measure, such as internal consistency. With regard to grouping survey items into categories, further analysis would suggest whether these items measure the same construct and could be considered subscales of the KoBF in future iterations. Further, establishing cutoff scores for adequate knowledge is also important in future KoBF survey development. Future studies should administer the measure to content experts (i.e., behavioral practitioners) to ensure that the newly-developed measure accurately examines knowledge of behavioral function.

Evaluation of duplicate response items suggests that participants were likely carefully attending to survey items, such that they responded similarly to a similar content question for two of the three response pairs. For the response pair related to the environmental reinforcement of behavior, differing response patterns often included participants endorsing the “Don’t Know” response option for one of the items. This finding suggests that item wording may have presented challenges for participants; however, future survey administration with behavioral practitioners should examine internal consistency of these items to determine whether they are measuring the same construct. In addition, in response to several participants sharing that the survey was time-intensive, the need for each item may be assessed to decrease survey duration and further improve the measure. Given that participants responded similarly to two of the three duplicate response pairs, future research should consider whether these duplicate

items can be reduced after administering the survey to a sample of behavioral experts to more accurately assess duplicate question response patterns.

Another strength of the KoBF survey is that it has the potential for use within other professional groups. In its current form, the KoBF discusses hospital patient severe behavior; however, survey items could be easily adapted to reflect autistic individuals who engage in severe behavior across settings and administered to different professionals, such as teachers and police officers. Further, after validation, the KoBF could be used as a pre- and post- training measure. A key takeaway from this study is that significant efforts need to be taken to improve physician knowledge of behavioral function, and measure administration before and after training may be a first step in evaluating training outcomes. Future training efforts targeting knowledge of behavioral function are important to improve the delivery of evidence-based and safe healthcare to all patients, particularly autistic patients who engage in severe behavior.

## **Chapter 3**

### **Study 2: Experiences and Knowledge of Multidisciplinary Behavioral Rapid Response Team Personnel**

#### **Method**

To address the absence of information related to BRRT personnel's knowledge of ASD and severe behavior, a qualitative study was conducted investigating training experiences and strategies used in the management of severe behavior. This study primarily used focus group methodology with a sample of BRRT personnel, followed by survey methodology to characterize the sample.

#### ***Participants***

Three virtual focus groups were conducted with a total of 11 BRRT personnel. Personnel self-defined their roles as physicians, nurses, social workers, security officials, and mental health technicians. A recent study indicated that these personnel are integral team members in the management of severe behavior for hospital patients with ASD (Salvatore et al., 2021). The overall sample of 11 participants included one physician, five nurses, two social workers, one security official, and two mental health technicians. Due to illness, one participant left the focus group discussion prior to its completion and did complete the post-group survey measures. The majority of participants were female (64%), White (54%), worked in a designated teaching hospital (90%), and were located in the Southeast geographic region (45%). See Table A9 for participant demographics.

#### ***Recruitment***

Participants were recruited from a representative sample of hospitals nationwide. A sample of hospitals was determined by randomly selecting 15 states, across each major



geographic region in the United States (i.e., Northeast, Southwest, West, Southeast, and Midwest), and identifying all hospitals in those states. The study team also attempted to recruit from hospitals across teaching status (i.e., teaching, non-teaching; Liu & Kelz, 2018). Hospital leadership and administrators (e.g., program manager or director, department chairs or heads, director of research) were contacted via phone calls and direct emails from the study team and asked to post flyers and share recruitment information with eligible participants.

### ***Procedure***

Focus groups were scheduled based on overlapping availability for participants. Evening and weekend times were offered based on prior focus group scheduling experience with hospital providers conducted by the study team and the potential for increased flexibility outside of traditional work hours (Marques et al., 2021). Prior to focus group discussions, interested participants were separated by occupation to ensure all perspectives were represented in each discussion then assigned to each group via random list generator to balance groups by demographic factors. At least one physician, nurse, social worker, security official, and mental health technician were initially assigned per group to ensure that all perspectives were represented; however, due to limited availability provided and lack of attendance, not all professionals were represented in each group. To promote adequate attendance, the study team overscheduled the number of participants per group based on prior experiences with no shows and last-minute cancellations. A total of 22 BRRT personnel expressed interest in the study; however, 14 participants were successfully scheduled for focus group participation. Out of 14 participants scheduled, 11 were included in the final sample.

Ultimately, virtual focus groups included three to five participants per group, which aligns with recent literature recommending limiting virtual focus group size due to increased technological demands and difficulty maintaining attention virtually compared to in-person (Marques et al., 2021; Smith et al., 2021).

The author was the primary facilitator, and a post-baccalaureate-level co-facilitator was trained to assist with conducting focus groups through formal didactic training and a mock focus group exercise. Virtual focus groups were conducted using Cisco WebEx®, a HIPAA-compliant video conferencing platform. Participant consent forms were reviewed, signed, and returned to the facilitator via email in advance. Participants were asked to log on from a private location with their video on and audio unmuted. The chat feature was disabled to more closely resemble an in-person focus group. A semi-structured focus group guide with open-ended questions was developed by the study team to elicit information about strategies and procedures used by BRRT personnel to respond to severe behavior within the general hospital patient population and with patients with ASD. Focus group guiding questions also explored training related to managing severe behavior with different patient populations, team member responsibilities and strategies used, documentation processes, and current needs related to treating patients with ASD who engage in severe behavior. See Appendix F for the question guide. Each focus group was conducted until the primary facilitator determined that saturation had been reached, wherein no new information was provided by participants (Braun & Clarke, 2006). The mean duration of focus groups was 70.3 min (range, 66 to 78 min) which is in line with recent guidelines stating that focus group

duration should be no longer than 120 min (Remler & Van Ryzin, 2021; Rupert et al., 2017).

Following focus groups, online questionnaires assessing knowledge of behavioral function (KoBF; developed by the study team) and knowledge of ASD (ASK-Q; Harrison et al., 2017b) were administered using the Qualtrics® survey platform (2021) to characterize the sample. See Study 1 for a description of measures. Responses were recorded anonymously. Participants received a single link to both survey measures so that they could complete the assessments at a convenient time, across multiple days, if needed. Surveys were administered after focus group discussions as the aim of the study was to solicit perspectives of participants on their experiences managing severe behavior in patients with ASD and the researchers did not want to inadvertently influence participants' perceptions with the types of questions on these measures. Although it is possible that participants' knowledge of ASD and behavioral function may have been influenced by other focus group members, focus groups were unlikely to result in increased knowledge due to this study involving no didactic instruction or facilitator feedback. Participants received a \$50 virtual gift card following their participation.

### ***Data Analysis***

Focus groups were video and audio recorded. Data were transcribed verbatim and thematically analyzed using the constant comparative method of qualitative data analysis (de Casterlé et al., 2020; Glaser & Strauss, 1967). The six phases of thematic analysis in psychology as described by Braun and Clarke (2006) directed the analysis: (1) building familiarity with the data, (2) identifying initial codes, (3) organizing codes into themes, (4) reviewing themes, (5) describing themes, and (6) writing and publishing. Data were

organized by identifying themes after the first focus group, comparing new data to existing themes, and creating new themes as needed when coding subsequent focus group data. Operational definitions of themes were documented in a codebook and revised as needed in the event of coding disagreements. Interobserver agreement was determined by a post-baccalaureate research assistant double-coding a sample of 33% of lines in each focus group transcript and comparing codes from the author. Percent agreement was calculated 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 segment of a participant response and the other coder providing no code). The secondary coder was trained by reviewing and coding a brief sample transcript to ensure coding accuracy of at least 90% three times consecutively with the primary coder. Interobserver agreement was 91.2%. Disagreements were all categorized as commission errors. After discussion with the secondary coder, it was determined that the secondary coder was hesitant to use several codes that required a specialized understanding of BRRT which decreased overall IOA. Following this determination, the study team revised the wording of these nuanced codes in the final codebook to promote clarity of the themes reported.

Salience was calculated by summing the total occurrences of each theme for each participant and across participants (Morgan, 1997). Each new rationale or repeated rationale provided by participants was counted as a separate occurrence. Participant and overall salience of each theme was determined using the following formula: (frequency of occurrences/total occurrences) \* 100. As a secondary indicator of salience, the number

of lines of transcript of each theme was calculated by counting the number of lines devoted to that theme in the transcription document. An occurrence of 1 was counted if a participant mentioned a theme in a whole line of the transcript. An occurrence of 0.5 was counted if a participant mentioned a theme up to one half of a line of the transcript. If a theme was mentioned greater than one half a line, it was counted as 1 mention.

Additionally, responses for each open-ended vignette question were scored as Correct, Partially Correct, and Incorrect identification of behavioral function. A scoring guide was created by the study team to classify correct, partially correct, and incorrect responses. See Study 1 for description. Interobserver agreement for correct responses was determined by a BCBA-D-level study team member double-coding all KoBF open-ended survey responses and comparing codes from the author. Scoring agreement was 97.5%.

## **Results**

### ***Themes by Salience***

A total of 11 themes and 37 subthemes were identified across the three focus groups. Themes and their corresponding subthemes were organized in order of salience. During the first focus group, all themes emerged, and no new themes were created in the final two focus groups. As such, three focus groups was deemed sufficient to represent the target population given that saturation was achieved (Braun & Clarke, 2006). See Table A10 for themes and descriptions ranked by salience. See Table A11 for the frequency and percentage of themes mentioned across focus groups. The mean rank order correlation between each focus group and the overall focus group rankings was 0.813 (range, 0.80 to 0.83) representing a strong positive correlation. Because there was an equal frequency for Themes 8 and 9 in the overall mention across groups, the number of

lines per theme mentioned by participants was considered to rank order these themes prior to the rank order correlation calculation. When comparing the top five themes in both the frequency and line mention indicators of salience, there was an exact match (100%). See Table A12 for themes by lines mentioned. The mean rank order correlation between salience indicators (i.e., by frequency of mentions versus by number of lines of mention) was 0.918, representing a very strong positive correlation. Given that both indicators of salience presented similar results, the frequency indicator of salience will be discussed moving forward. The top five most salient themes will be described first; remaining themes will be grouped by category for ease of interpretation. The five most frequently endorsed themes included:

1. Various alternative strategies to restraint are implemented by BRRT across patient populations.
2. The purpose and procedures of BRRT vary by hospital.
3. There are several indicated weaknesses of BRRT and potential areas for improvement.
4. Hospitals have specific debrief and documentation processes after BRRT call.
5. Hospitals have differences in BRRT training across personnel and differences in team membership credentials.

**Alternative Strategies to Restraint (Theme 1).** The most salient theme reported by BRRT personnel was that they use alternative strategies to restraint for all patients, irrespective of an ASD diagnosis. Behavioral emergency response team personnel described various strategies they have used personally or observed their colleagues use other than restraint. Subthemes included: (a) communicating with the patient, (b)

developing rapport and individualizing strategies, (c) understanding behavior triggers and the reason for the behavior, (d) providing space and promoting de-escalation, and (e) removing physical items in the room. For example:

P3: I'm always just trying to listen as soon as I get there, just listen to the patient, actually hear them. (Theme 1; Subtheme a)

P6: I just immediately start with rapport building. (Theme 1; Subtheme b)

P5: We get information that's helped them be more at ease when they're in the hospital setting, such as being away from family, some kids have a thing about touching and it's like you can't just touch me. We want to be able to assess and know that [information] to provide good care. (Theme 1; Subtheme c)

P4: If they escalate, then typically, we remove ourselves and let them calm down and then come back later on. (Theme 1; Subtheme d)

P10: Some of their personal belongings can't be in rooms, obviously, ligature risk factors and general safety factors for themselves and others. (Theme 1; Subtheme e)

**Differences in BRRT Purpose and Procedures (Theme 2).** The second most salient theme included participants describing the different responsibilities, organizational structure, and procedures of BRRT at their institutions. Subthemes included: (a) multidisciplinary team composition and collaborative approach, (b) purpose of the team to respond to patient behavior, (c) procedure to activate BRRT, and (d) purpose of the team to respond to staff/visitor behavior. Examples of different descriptions included:

P10: We are made up of eight individuals. Seven of us are nurses, and then [Name] is our tech on our team and so we cover six different areas of our hospital. (Theme 2; Subtheme a)

P5: Our supervisor's present, our behavioral mental health nurse is the lead, we also have the patient's primary or assigned nurse that will also be available, and there have been times when psych, psych consult would show up in the ED then if it's in the ED, we actually have a nurse, a psych nurse practitioner that's present. (Theme 2; Subtheme a)

P3: I would say our BRRT was created to decrease staff assaults, to also increase patient safety and increase resilience and with the staff in general we're unionized at our hospital too, there was a big push with the union to have some type of intervention due to the staff assault. Which, I am proud to say, have dropped significantly. (Theme 2; Subtheme b)

P6: We wanted to avoid code grays or having to restrain patients, and we wanted to get early intervention and medications implemented if possible. And [BRRT] was kind of, our way ... to really give priority to the psychiatric patients that were there in the hospital. (Theme 2; Subtheme b)

P6: At my hospital, what we do overhead, if it was a code blue code gray, we just ... anybody on any of the floors, whether it be, ER, throughout the hospital, just dials a number and says, "BRRT to med surg." "BRRT call to blah, blah, blah, wherever." (Theme 2; Subtheme c)

P9: For us there's a little button, and it's only located underneath the desk. It's only located though in all the medical exam rooms and the front desk, and they can alert it. What happens when they press that button all of the computers, for example, my computer just, shuts off of, like Epic. We use Epic. And then it's a white screen that comes, "safety alert." And then it shows us, you know, where it is and things like that. That's how we get alerted. For us, we can dial out if we have it. (Theme 2; Subtheme c)



P11: We also ... handle calls with staff. Last time that happened was, that's been a minute for me anyway, was we had a very young nurse, lost her first code and she was very upset. And just how do we get them off the floor and what can we do and how do we break them out and can we go back to work? Or should they go home or whatever? It was just one of those, we also offer staff support, as well. (Theme 2; Subtheme d)

P6: And then we also help assist with our team when we get agitated visitors or family members because that can be problematic for folks as well. (Theme 2; Subtheme d)

**BRRT Weaknesses and Improvements (Theme 3).** The third most salient theme was that participants reported several weaknesses and suggested improvements for BRRT. Subthemes included: (a) staffing challenges, (b) misalignment of calls with need and inappropriate calls for BRRT, (c) lack of training/retraining, and (d) need for autism-focused training. Examples included:

P4: Honestly, I think we probably just need more staffing ... But our team can only do so much 'cause we have one team per hospital. I said, sometimes it's one nurse, one tech, you know so if I've got a BRRT here, then I got a BRRT here and then I got a BRRT one time, I had five BRRTs back-to-back, and I can't stay and help. I'll say that's a big thing. (Theme 3; Subtheme a)

P11: They'll call us the most... They just get so anxious about reading any kind of psych history, but they're here for a foot injury or whatever. If that plays into it, yes, we can come up. But we'll, we'll help you. We'll round, game plan, or whatever. But a lot of that is just, I was talking earlier that anxiety about, oh, it's a psych patient. Well, is it, you know, it's just a person in front of you, who has a medical issue. (Theme 3; Subtheme b)

P1: I think there's always room for retraining or like refreshers. It takes time and resources. (Theme 3; Subtheme c)

P10: We are starting to see more [autistic] individuals, but we do not have specialized training for it. (Theme 3; Subtheme d)

**Debrief and Documentation Processes (Theme 4).** Behavioral rapid response personnel also reported that they follow specific debrief and documentation processes after a BRRT call which vary by institution. Subthemes included participants describing: (a) the items included in documentation; (b) the debrief process with patients, visitors, and staff; (c) which professional completes the debrief process; and (d) which professional completes documentation. Examples included:

P6: I developed a form that gets scanned into my database. I know which BRRT person responded, what they did, what was the call for. Was it a patient? Was it a visitor? What was our intervention? And it's all coded, I can keep the stats for that. (Theme 4; Subtheme a)

P10: We do have a set BRRT note that we put in everybody's EMR chart anytime that we see a patient. It kind of reviews who called us. What were the actions going on? How did we find the patient? What did the patient report? And then kind of our recommendations to move forward for that. Every time that a BRRT gets a call, that note goes into their chart, which will stay in their chart indefinitely. (Theme 4; Subtheme a)

P7: We do something called a patient debrief that has to be completed in an hour or two if restraints are implemented and then within a day if no restraints are implemented, and then that patient will get added to the rounding list that I mentioned earlier so that we

have kind of regular eyes and ears on them while they continue to stay in the hospital.

(Theme 4; Subtheme b)

P9: If we do have a safety alert that we have to respond to, we do have a huddle at the end to discuss things that we could have improved on. What happened? If anyone else needs support afterwards. (Theme 4; Subtheme b)

P2: The health supervisor does a debrief like immediately after the team members or the nurse or whoever called the BRRT and was involved in that situation. If the behavioral restraint was used then psychology will go back. (Theme 4; Subtheme c)

P1: Typically, with us, if it's a very extreme situation, there will be a debrief with security, psychology, and nursing staff but if it's a typical restraint, it's nothing further. (Theme 4; Subtheme c)

P3: After every BRRT, one of the members documents the encounter. (Theme 4; Subtheme d)

P4: Now, I know for when they call a BRRT or code, which is a code green, security typically does that documentation because they're the lead on that (Theme 4; Subtheme d)

**Differences in Training and Credentials (Theme 5).** Behavioral rapid response personnel indicated that their institutions lack standardized training and team membership requirements. Subthemes included differences in the: (a) type of physical management training provided to core BRRT and non-core BRRT personnel, (b) BRRT membership requirements, (c) general training and responsibilities across BRRT personnel and other healthcare providers, and (d) frequency of physical management training and/or retraining for BRRT. Examples included:

P8: I do believe security originally was trained with, I want to say CPI, but I cannot totally remember, but it was a different form and we're having to kind of re-educate security on how to do these safe and ergonomic and equally as effective holds that aren't quite as traumatic or as aggressive as CPI holds are. I've seen some of them being done by other people and they're just- they're a lot different from what we do with the MCPP. (Theme 5; Subtheme a)

P3: I think hiring wise, they required at least one year of psychiatric nursing in a charge nurse position when they created our team. Otherwise, they, we created it from the ground up, there wasn't any training or anything it was just our backgrounds. Everyone in my team has tons and tons of experience in psychiatry, residential adolescent corrections, a couple of us are from corrections, and some of us have med surg. It was kind of a good you know different variations of psychiatry that we all kind of covered. (Theme 5; Subtheme b)

P2: We really don't have any other requirements. We don't have many people that even have any psychiatric nursing background but that was another benefit, we were hoping, for the program that we would take these hopefully low frequency but high impact situations and we would expose a select group to those repeatedly so they'd get better at responding over time. (Theme 5; Subtheme b)

P10: If we are both called for an aggressive patient, security and simultaneously when we enter the room security knows that this is like, our specialty of debriefing and, like, calming individuals down. Security will often step out of the rooms and allow the BRRT staff to kind of take over the de-escalation if possible. But they will remain there if things were to escalate or if the patient would need restraint. (Theme 5; Subtheme c)

P7: I want to say two or three times a year where we do an in-person simulation kind of training. Do we remember how to do restraints, which restraints, how to do this hold and that hold and then we, we also do some, sometimes we'll do on-site training with some of the staff depending on kids and acuity. (Theme 5; Subtheme d)

P9: Our re-training happens, three or four times a year. We need to get certified and things like that. (Theme 5; Subtheme d)

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

### **Factors Influencing BRRT Response.**

*Hospital Characteristics Influencing BRRT Response (Theme 6).* Behavioral rapid response team personnel indicated several hospital characteristics that influenced the response of BRRT. Subthemes included: (a) hospital resources available or lack thereof, (b) time for chart review or gathering information about the patient, and (c) limited physical space. Examples included:

P8: We have equipment to kind of manage that or keep ourselves safe... that's something that our hospital supplies us with but we also have a closet full of all kinds of de-escalating sensory toys and things like that. (Theme 6; Subtheme a)

P3: If we don't have time we don't look at the chart at all, we just go straight there and just observe when we get there. If it's a nonemergent call and they're like "hey this guy's been a little kind of a jerk today, we don't know if he's confused or what's going on" then we'll look through the chart and see what's going on. (Theme 6; Subtheme b)

P12: The new hospital will literally double the beds in every room. They'll be private now which will be helpful for all. We have a lot of semi-private rooms now but

the new hospital literally doubles the number of patients, inpatient beds, but all will be individual rooms which is helpful for our response. (Theme 5; Subtheme c)

***Interpersonal Characteristics Influencing BRRT Response (Theme 10).***

Behavioral rapid response personnel indicated interpersonal characteristics and team dynamics influencing the response of BRRT. Subthemes included: (a) lack of organization or communication, and (b) good communication among the BRRT and with other healthcare providers.

Examples included:

P1: We were told that only two security officers are supposed to respond and see if more personnel are needed. But it's usually like six people showing up and it's a mess. (Theme 10; Subtheme a)

P3: I will say my group of people that I have now, the eight of us get along so well, and we just work so well, that in a crisis it's almost like none of us have ever experienced anything else. It's like our hiring manager did such a good job plucking all of us out of our different areas and different hospitals and putting us all together. Because we're all very comfortable with each other. We learned quickly what everyone's skills were and where everyone lays. (Theme 10; Subtheme b)

P9: We always work with each other. If it's not within our team, we work with each other in a different role. Especially, with nursing, we're kind of, I always say that we're kind of like the mitochondria of the cell so we have our hands in a little bit of every pot. For me, I feel I interact well with everyone. (Theme 10; Subtheme b)

## **Factors Influencing BRRT Call.**

### ***Perceived Knowledge Deficits and Negative Perceptions Influencing BRRT Call***

(*Theme 8*). Behavioral rapid response team personnel reported that a gap in knowledge and negative perceptions of patients from healthcare providers outside of BRRT commonly lead to a BRRT call. Subthemes included other healthcare providers: (a) lacking knowledge and alternative strategies to restraint, and (b) making negative assumptions about patients served. Examples included:

P1: Sometimes nursing staff and other staff can actually escalate the patient. Sometimes it's about de-escalating the staff and the patient at the same time. When would you call a BRRT? You wouldn't wait ... (Theme 8; Subtheme a)

P9: It's a lot of education for [other] staff because it took a long time for me to understand. I used to think you're going to give them the PRN when they're like, throwing everything around. Absolutely not ... You get to kind of, especially if you know your patients and you see them, you know all the time through your shifts, you can see their kind of signs, ... The signs that you're like oh, okay, come on friend, ... just try to see, those are like the signs before you can prevent an issue, a bigger issue. (Theme 8; Subtheme a)

P3: We often get a lot of push back and negative statements from the staff. I think there's a lot of frustration from the [other] staff when they have to 'deal' with some of the more aggressive and not typical behaviors. They'll say, 'this is a psych thing' so we're called. (Theme 8; Subtheme b)

***Patient Mental or Behavioral Health Influencing BRRT Call (Theme 11).***

Behavioral rapid response team personnel indicated that patient mental or behavioral health diagnosis or behaviors in the absence of a diagnosis often lead to a BRRT call.

Examples included:

P11: We're answering calls from people we don't know. We usually, when we get calls we're going to ask some triage questions. You know, what do they have available? What's going on with them? How far from baseline is this? We get anything from post-surgery delirium to well, we had a psychotic visitor ... (Theme 11).

P3: Those are typically warranted just because we try to tell the staff all the time pacing can be a sign of agitation. If they're calling us like "hey this patient is pacing, I don't know them but they're pacing" we are absolutely okay and happy to respond to that (Theme 11).

**Use of Restraint Overall and Alternative Strategies to Manage Severe Behavior for Autistic Patients.**

*Use of Restraint to Manage Severe Behavior (Theme 7).* Behavioral rapid response team personnel described their use of restraint during their BRRT response. Subthemes included describing: (a) that restraint strategies differ by professional, (b) their process of following a hierarchy of implementing least-to-most intrusive strategies, (c) use of chemical restraint, and (d) use of physical or mechanical restraint. Examples included:

P11: If they're calling me [security] then we're going hands on. (Theme 7; Subtheme a)



P5: Even with the presence of security, we're making sure they're not so immediate in their response. (Theme 7; Subtheme a)

P10: But it's definitely that de-escalation for us and then PRN medications if needed. (Theme 7; Subtheme b)

P4: When patients come in if they're in severe crisis and they're aggressive, [BRRT] typically IM [intramuscular] them if they can't get them to de-escalate and they're physically going after people, then they'll, they'll give them IMs. (Theme 7; Subtheme c)

P1: I know sometimes we'll get a call for patient assaulting staff and typically if it's, we'll use four lock leather restraints. (Theme 7; Subtheme d)

P7: ... and then I go into a what we call it a backward assist ... You go into that full range of control, but it's not uncomfortable, it's not threatening. You're just holding them to get them onto the bed, get them de-escalated (Theme 7; Subtheme d)

***Alternative Strategies Used for Patients with ASD who Engage in Severe Behavior (Theme 9).*** Behavioral rapid response personnel identified use of alternative strategies to restraint for patients with autism. Subthemes included: (a) understanding reasons for severe behavior, (b) building rapport, individualizing strategies, and communicating with the patient, (c) adapting medical procedures, and (d) coordinating with other providers prior to working with patients with autism. Examples included:

P7: And what I see is that you know, as especially our ASD patients use externalized behavior to communicate, or to express pain or, you know, just, you know, as part of their daily life it's not always interpreted as a symptom. (Theme 9; Subtheme a)

P11: We'll have brief things like they don't like hearing the word 'no' and we get a list of triggers and what they expect of us in our response. Usually, the acute care plan is how that is handled. (Theme 9; Subtheme a)

P3: I would say with those, we typically involve the family. With patients with autism we'll very strongly involve the family when we can. What did they dislike, tell me their triggers. Tell me what not to say because sometimes it's just something as simple as that. Don't say 'home' like make sure you say 'grandma's' or something like that. I say we rely pretty heavily on the family when we can to help us with that and provide a lot of comfort items. (Theme 9; Subtheme b)

P10: Oftentimes it's ... allowing that patient more time to process that information compared to .... if I would go in and be like, 'hey, I need to get your vitals. I'm gonna do a lab draw easy peasy.' I'm gonna just break it down super simple, maybe focus on the one thing that you need to achieve most that shift and let the others go. And if you have good luck, then maybe in a couple hours, you can request the second thing. Giving them more time to process information. (Theme 9; Subtheme c)

P3: We're lucky that most of the time we have a little bit of a heads up if a patient with severe autism is coming in... (Theme 9; Subtheme d)

### ***Knowledge of Behavioral Function***

Survey responses to the KoBF were collected from 10 of 11 participants. Participants obtained a mean total score of 32.9 out of 47 ( $SD = 5.1$ ; range, 24 to 40). In the KoBF Statements subscale, participants obtained a mean score of 17.3 out of 27 ( $SD = 5.4$ ; range, 5 to 23). In the Vignette subscale, participants had a mean score of 15.6 out of 20 ( $SD = 2.1$ ; range, 13 to 20). A total of 63.6% participants scored a 70% or above.

See Figure 5 for KoBF total scores by participant. See Figure 6 for percent correct scores by subscale. Across the four vignettes, 15% of open-ended responses were scored as correct. Vignette 3 had the highest percentage of correct open-ended responses (30%). See Figure 7 for percent correct and partially correct scores for each vignette.

### ***Autism Stigma and Knowledge***

Survey responses to the ASK-Q were collected from 8 of 11 participants. The participant that was unable to participate in the full focus group did complete the survey and the remaining two did not respond to the study team's requests to complete the survey. See Figure 8 for ASK-Q total scores by participant. Seven out of 8 participants (87.5%) demonstrated adequate knowledge of autism with a total mean score of 41.3 out of 48 ( $SD = 4.6$ ; range, 33 to 47). For the diagnosis/symptoms subscale, participants obtained a mean score of 15.1 out of 18 ( $SD = 2.9$ ; range, 12 to 18). For the etiology subscale, participants obtained a mean score of 13.3 out of 16 ( $SD = 1.6$ ; range, 11 to 16). For the treatment subscale, participants obtained a mean score of 12.9 out of 14 ( $SD = 1.0$ ; range, 11 to 14). On the stigma subscale, participants endorsed 0 out of 7 items, indicating no evidence of stigma. See Figure 9 for ASK-Q percent correct scores by subscale.

### **Discussion**

This study provides vital information about BRTT personnel's experiences with patients with ASD who engage in severe behavior, their training experiences, and the strategies used in the management of severe behavior. The aim of this qualitative study was two-fold: (a) to gather first-hand information about the functioning of BRRT; and (b) to assess whether BRRT personnel have the advanced training and specialized resources

needed to best meet the needs of patients with ASD who engage in severe behavior. The existing BRRT literature has largely focused on decreasing instances of patient aggression (e.g., Pestka et al., 2012) and decreasing the need for restraint (e.g., Zicko et al., 2017); however, the current study aimed to extend the literature beyond effectiveness to explore the ability of these teams to serve neurodivergent patients. This study also extends the field of research aimed at improving the quality of healthcare delivered to patients with ASD (e.g., Zerbo et al., 2017).

By thematically analyzing qualitative data from our focus groups, we were able to identify salient themes that consistently appeared across focus group participants. Namely, we determined that BRRT use alternatives strategies to restraint across hospital patients, that the purpose and procedures of BRRT vary by institution, that there are noted weaknesses and areas for improvement of BRRT, that different institutions have established debrief and documentation processes, and that BRRT teams have a gap in training. Further, participants described different factors that influence the BRRT call and response and different strategies that their teams implement when responding to severe behavior. Our sample was not restricted by geographic region or credentials, which allowed for gathering the perspectives of multidisciplinary BRRT personnel nationwide. Hospital systems across the country were strategically targeted by the study team to understand how these teams operate within different hospital systems.

The most salient theme identified by participants was that a wide range of strategies other than restraint are used in the response of BRRT. Participants mentioned strategies including personnel lowering the volume of their voice and being aware of their vocal tone, placing a significant emphasis on building rapport and individualizing

their approach, and allowing the patient physical space and/or time to de-escalate. Although participants were describing strategies used across all patients, the listed strategies would be appropriate in responding to patients with ASD who engage in severe behavior. Given the core features of ASD and varied experiences across the autistic population, BRRT personnel could use several of the aforementioned strategies in responding to autistic patients. For instance, an autistic patient may benefit from a lowered vocal tone and increased physical space from BRRT when responding to severe behavior that occurs in a loud hospital environment with many providers in close proximity. Individualization of strategies used may also benefit the BRRT response for patients with ASD given that these patients may have different interests, preferences, and patterns of communication. As such, individualizing strategies can provide integral information on why the behavior is occurring and how to best meet the needs of the patient. In addition to applying strategies to the neurotypical population, the many alternative strategies to restraint identified by BRRT personnel are easily transferrable to providing high quality care to autistic individuals in the hospital setting. The alternative approaches described by participants appear to be compassionate and patient-centered, which may suggest that BRRT are taking steps toward their goal in reducing restraint implementation and have the capability to work with autistic hospital patients. This finding aligns with results of prior studies demonstrating the effectiveness of BRRT at reducing restraint use (Zicko et al., 2017).

Further, our focus group participants described a “hierarchy” or staged approach to restraint. Once alternative strategies have been implemented and show no effect at decreasing the rate or intensity of severe behavior, BRRT personnel indicated that they

follow a staged approach to restraint, using least-to-most intrusive restraint procedures. The use of this restraint hierarchy is not unique and can be found in previous investigations of physicians' response to hospital patient severe behavior (Salvatore et al., 2021). Although this study is consistent with prior research that indicated use of a staged approach to restraint, this study is novel in that it extends the literature by more thoroughly understanding which alternative strategies are used by BRRT personnel to manage hospital patient behavioral emergencies.

Although alternative strategies appear to be prioritized, it must be noted that restraint is still used by these teams in responding to patient severe behavior. This point was further supported by multiple participant responses endorsing use of physical, mechanical, and chemical restraint. Interestingly, in one focus group, participants preferred for chemical restraint to be referred to as "intramuscular" or "IM," stating that this procedure is not restraint given that the patient becomes sedated immediately after the medication is administered. On the contrary, researchers in the published literature define chemical restraint as the process of using medications to control or manage aggressive behavior without specifying that the patient must remain awake (Friedman & Crabb, 2018). Although participants reported that their typical response is not restraint, BRRT personnel described restraint as sometimes necessary to "contain" severe behavior and "protect everyone and keep us nurses safe." Given the many work responsibilities of BRRT and the volume of calls described by participants, reliance on restraint may appear to be a quicker and more effective means to promote patient safety and minimize further harm to oneself, others, or property. However, there are many adverse effects of restraint for patients with ASD, including distrust of medical professionals (Wong et al., 2022),

feelings of powerlessness, humiliation, and distress; serious injury; risk of psychiatric symptoms; and even death (Perers et al., 2021). Given the literature focused on the overreliance on restraint for autistic patients (e.g., O'Donoghue et al., 2020), future research should continue to investigate the staged approach to restraint mentioned by participants and, in turn, use this information to provide enhanced training on alternative strategies to further reduce restraint. This type of training would not only be helpful for team personnel but also for healthcare providers broadly to further mitigate restraint use and protect the health and safety of all parties involved.

Another salient theme identified by participants was that BRRT structure varied across hospital systems. Participants provided information ranging from the established purpose of the team at their hospital to different procedures regarding responding to patients, staff, and caregivers. Although most participants described their purpose to respond to patient emergent unsafe and dangerous behavior, the various roles of BRRT personnel appeared to be dependent on the institution. For example, participants indicated that they respond to different types of people, such as some teams exclusively responding to patients while others respond to patients, staff, and visitors' emergent and dangerous behavior. As such, generalizations about BRRT are difficult to make in the literature and individual hospital systems should ensure that the purpose of BRRT is explicitly clear for everyone at their institution to maximize the effectiveness of these teams.

In addition, BRRT personnel identified different debrief and documentation processes that were established by their institutions. Although most participants indicated that their team's response to a call is documented, it is critical to understand how this documented information is used to inform future care for that patient and future BRRT

responses. A few participants described the use of an online tracking sheet to track restraint information such as who was restrained (e.g., patient or visitor), which BRRT personnel responded, strategies used, and reason for BRRT activation. The wide-scale adoption of tracking systems across BRRT nationwide may be helpful in identifying common reasons for BRRT activation, topographies of severe behavior displayed during the response, and strategies used. In the future, it would be important to better understand the differences in response by type of severe behavior displayed and use this information to inform BRRT intervention. In terms of debrief procedures, our study findings are promising as they indicate that BRRT typically have existing debrief and documentation policies. Given that participants described differences in these processes following BRRT response, a future research avenue would be to investigate the impact of these differences in debrief and documentation procedures on patient outcomes and staff satisfaction. Specific to instances of restraint implementation, all institutions should debrief with patients as there are a host of adverse consequences to restraint. Sufficient follow-up and debrief processes may work together to minimize the potentially negative impacts of restraint. Fortunately, each represented institution appeared to have unique strengths and some differing needs for BRRT that could contribute to nationwide development and improvement of such teams to meet the needs of their institution. The broader purpose of this study was to describe BRRT personnel experiences and training rather than discussing best practices for BRRT. Future research should aim to evaluate patient-centered outcomes and how outcomes differ based on factors described by BRRT personnel. For future BRRT improvements nationwide, it is important to know which



intervention strategies, training, and debrief procedures will lead to the best possible outcomes for autistic patients who engage in severe behavior.

Consistent with prior research, BRRT personnel described their teams as multidisciplinary, with their teams consisting of professionals from many different areas of expertise. Whereas previous research focused on standard team composition and operation across individual institutions (Lelonek et al., 2018), the current study was novel in that it gathered the experiences and perspectives of a sample of BRRT personnel across several different institutions across the U.S. Although BRRT personnel described the multidisciplinary nature of their teams as a strength, BRRT personnel indicated the importance of collaborating with other healthcare providers beyond their specific team. A few participants expressed that by collaborating with both multidisciplinary team members who are part of BRRT and those outside of BRRT, the patient's health needs can be better addressed. Given that many other professionals are a part of a patient's care, it is important that BRRT personnel collaborate to address the patient's overall needs outside of their brief patient interaction.

In contrast, BRRT personnel reported barriers to collaborating with those outside of BRRT. One barrier to collaborating with healthcare providers outside of BRRT includes a lack of training about neurodevelopmental differences and having preconceived notions about patients with psychiatric or behavioral concerns. For example, other healthcare providers were reported to use stigmatizing terms such as "crazy," "dangerous," or "threatening" when referring to patients with severe behavior. Another barrier to optimal collaboration described by participants across hospitals was the misunderstanding of when to activate BRRT. Participants explained that their teams

may be activated during less urgent patient behaviors and not activated when patients' behavior is unsafe and interfering to themselves and others. Training covering when to activate BRRT would be helpful in mitigating the misalignment of calls with the patient's behavioral need and in optimizing collaboration with healthcare providers.

In combination, the reported negative perceptions and the frequent misalignment of BRRT call with need, necessitate improved training for other healthcare providers outside of BRRT personnel. Based on study findings, recommended hospital-wide training may include a list of BRRT personnel and their credentials, activation procedures, examples of scenarios where it would be appropriate and inappropriate to activate BRRT, and what other hospital providers might expect when a BRRT responds. For instance, if other healthcare providers better understood the purpose and procedures of when to call BRRT, team personnel could hone their energy and responses to patients with true behavioral emergencies and take the time to implement, perhaps more time-consuming, alternative strategies to restraint. Taken together, the negative perceptions of patients with mental health concerns and overreliance on BRRT for patients with psychiatric diagnoses suggest the need for enhanced training to promote a compassionate and unified multidisciplinary response to neurodivergent patients and patients with a mental or behavioral health history.

In addition to the need for hospital-wide training, participants described potential areas for improvement within BRRT. Identified areas of need included improved training, staffing, and co-location within the hospital. Primarily, participants described how differences in training across personnel impact the overall functioning of the team. A consistent training approach across all multidisciplinary personnel would assist BRRT in

more quickly and effectively responding to patient unsafe and interfering behavior. Participants also discussed differences in their BRRT responsibilities, such as having either full-time or partial-time BRRT responsibilities, second to their primary roles. As reported by participants, it would be helpful to team functioning and patient care for personnel to hold a dedicated BRRT role rather than juggling multiple job responsibilities. Relatedly, participants described that BRRT are often not staffed in hospitals 24/7, which presents occasional challenges such as an inconsistent response to patient severe behavior. In addition, participants reported that co-location on patient floors and hospital departments is important for an improved and quicker response to not only patients but other healthcare providers who may access BRRT. Consistent BRRT presence, accessibility, and awareness that BRRT exist as a specialized team to respond to patient emergent behavior are important to maximize BRRT effectiveness. Prior research widely focuses on the many benefits of these teams and who make up the teams (e.g., Lelonek et al., 2018; Loucks et al., 2010; Pestka et al., 2012; Zicko et al., 2017) which is vital information; however, this study presents the important perspectives of team members to further improve BRRT as a whole. These findings are significant because they provided valuable insight from actual team members on their day-to-day BRRT experiences which can be used to further improve the quality of BRRT. Given our nationally representative sample, these shortcomings appear to exist across hospitals and should be considered in conjunction with the many identified strengths of BRRT, such as coordination and communication, in the future development and expansion of BRRT nationwide.

Participants also identified several shortcomings of their teams that directly relate to meeting the needs of patients with autism who engage in severe behavior. A major finding from the current study was that BRRT are not specifically trained for working with autistic patients across the hospitals sampled. Participants often described responding to patients with autism; however, when directly asked about how to respond to a call for a patient with autism, participants shared fewer treatment approaches compared to responding to a neurotypical patient or a patient with more severe mental health concerns. Although participants described various general strategies that they have found to be effective, such as individualizing their approach and collaborating with multidisciplinary providers, it is important to highlight that alternative strategies to restraint for patients with autism specifically were less frequently discussed. The finding that BRRT personnel do not receive ASD-specific training, alongside the continued implementation of restraint, suggests that BRRT personnel, while specialized, could benefit from further knowledge and comfort in responding to autistic patients who engage in severe behavior. When discussing neurocognitive disorders, such as dementia, there appeared to be a better understanding of how to respond in comparison to patients with autism. Given the increasing prevalence of patients with autism seeking medical care and the higher likelihood of severe behavior in this population, it is imperative that BRRT are appropriately prepared to respond to their unique needs. For example, autistic patients may have different sensory needs than the neurotypical patient population that are already unaccounted for in hospitals (e.g., bright lights, loud noises, crowded environments) and should be considered in a BRRT response to an autistic patient. Taken together, an increased understanding of autism and behavioral function may result in a more

compassionate and informed lens when approaching a patient with autism who engages in severe behavior.

Similarly, BRRT personnel described a lack of autism-specific resources and knowledge. Although most participants in this sample demonstrated overall adequate knowledge of autism, this knowledge does not correspond with appropriate and/or efficient BRRT professional practice. For instance, possessing sufficient knowledge about the core features of autism does not translate to having the practical skills needed to best serve patients with autism. In addition, participants in this sample demonstrated a gap in knowledge of behavioral function, as indicated by low KoBF scores and incorrect attributions of severe behavior in open-ended responses. In line with the need for additional training and resources, BRRT personnel may benefit from training programs focused on promoting knowledge of behavioral function. Future training may also include examples of other common topographies of severe behavior and common antecedents that evoke and consequences that maintain severe behavior in a hospital setting. This knowledge could then help team members form hypotheses about why severe behavior may be occurring based on the environmental information available to them. Ultimately, training should inform and guide their response procedures.

Given the depth of literature demonstrating that treatments targeting function are more effective than non-function-based approaches (Campbell, 2003; Heyvaert et al., 2014), a dedicated effort to increasing provider knowledge of behavioral function is likely to guide more effective BRRT responses. Currently, participants indicated relying on caregivers to provide important information about the patient and beneficial response strategies. Although caregivers can be helpful in providing this information, we cannot

ultimately rely on caregivers' assistance or assume that all patients with ASD across the lifespan will be accompanied by caregivers; therefore, BRRT personnel must be better prepared to respond to this patient population independently. Advanced training in autism and behavioral function is recommended to promote the safest and most effective healthcare provided by team members. Although such training would require a resource and time investment, it would likely lead to fewer worker compensation reports and associated expenses, and most importantly, promote the safety of patients and providers alike. In a scoping review, Fricke et al. (2022) described the occurrence of unsafe and interfering patient behavior as steadily increasing which, in turn, places great financial strain on hospital systems. With this information in mind, valuing the perspectives and wealth of knowledge that BRRT personnel possess is an important next step in increasing safety for all parties and decreasing incurred costs for the hospital. Such training opportunities may not only increase knowledge and usage of these teams but help foster a collaborative two-way relationship between teams and other healthcare providers to promote a safer, healthier environment for all.

Given that BRRT personnel described different membership requirements across hospitals, an effort to standardize the competencies and skills needed to be part of BRRT is recommended. Beyond the description of standard background and credentials (e.g., Bachelor of Science in Nursing, Registered Nurse), participants reported that there are no specific skills-based requirements for team membership. Future studies should explore the interpersonal skills and other qualities of team members that are most beneficial in promoting team cohesion and managing hospital patient severe behavior in a quick and safe manner. As in the MCPP training program, a minimum passing requirement

following a role play may be established to more accurately and reliably measure the skills needed to be part of BRRT (Bernstein et al., 2022). Participants also reported that training in physical management may vary by provider. For instance, it was often reported that security receives different physical management training than other team personnel, which contributes to a lack of team cohesion, communication, and collaboration in BRRT response. In combination, a lack of standardized skills and communication can greatly limit the overall effectiveness and quality of BRRT. As aforementioned, previously published studies have investigated the types of professionals on these teams; however, more quantifiable data are needed on the necessary members of these teams and the most effective trainings. Future research should consider exploring how credentials, skills, and training impact measurable outcomes of BRRT effectiveness.

This study is not without limitations. Due to significant recruitment difficulty, our sample size was relatively small compared to the total number of identified teams across the United States. Our sample was also limited by provider type as many participants were nurses. An overrepresentation of nurses may have impacted the information gathered in this study based on differences in training models across professions. For instance, nurses primary mode of training falls within the medical model while security officials are more likely to be trained in how to physically manage emergent patient behavior. We were unable to solicit the perspectives of many physicians and security officials who are equally integral members of these teams; as such, this study should be replicated with an overrepresentation of these types of personnel. Additionally, our sample was largely comprised of BRRT personnel working within teaching hospitals. It is unclear whether BRRT are more prevalent at teaching hospitals that are affiliated with

academic institutions and such a hospital background may have impacted study findings. Future research may consider investigating whether BRRT experiences differ based on hospital status, geographic location, and types of patients served.

Qualitative information gathered in this study also presented several avenues for future research. Participants described a lack of resources as contributing to challenges in their response to severe behavior. Future investigations may seek to understand how hospital factors, such as hospital type, geographic location, and predominant patient populations served, influence the resources and training available to BRRT personnel. Participants also identified differences in personal protective training programs, such as some appearing to be more focused on crisis prevention and others focused on physical management of emergent behaviors. Future research may consider how training received by BRRT personnel impacts use of alternative strategies compared to use of restraint. Nonetheless, the themes that emerged were consistently identified across participants from different hospitals in varying geographic regions and provide valuable insight into the experiences of BRRT personnel.

A key takeaway from this study includes the need for specialized training in ASD and severe behavior which could lead to two different avenues for BRRT in the future. First, trained BRRT members could be designated as ASD experts and ensure that at least one expert is present for all responses for diagnosed or suspected patients with autism who engage in severe behavior to model appropriate implementation of skills. Second, BRRT personnel with specialized ASD training could create an autism-specific BRRT that exclusively responds to autistic patients. This second suggestion would be more representative of current rapid response teams, such as some teams that specifically



respond to psychiatric patients (Carpenter et al., 2013) and other teams that respond to medically complex patients (Buist et al., 2002). Although all hospital personnel should receive training on autism and behavioral function, by incorporating specialized training within BRRT, these BRRT personnel may be sufficiently prepared to respond to patients with ASD in emergent situations. The themes that emerged from qualitative participant responses serve to guide future research in increasing safe, effective, and compassionate treatment of hospital patients with ASD who engage in severe behavior.

## **Chapter 4**

### **General Discussion**

This study provides important information about hospital providers' experiences and knowledge in working with patients with ASD who engage in severe behavior. The aims of this project were to (a) assess knowledge of behavioral function across physicians and medical trainees and (b) gather qualitative information about how BRRT personnel respond to severe behavior across patient populations. The current work was novel in that it focused on the specific group of autistic hospital patients who engage in severe behavior. A major conclusion from this two-part study was that there is a gap in hospital provider training on autism and on behavioral function. Multidisciplinary provider training in these areas is critical as it is well documented that the prevalence of ASD is increasing (Maenner et al., 2023), autistic individuals have higher healthcare needs than the general population (Lokhandwala et al., 2012), and individuals with ASD are more likely to engage in unsafe and interfering behaviors (Steenfeldt-Kristensen et al., 2020) that may occur while receiving medical care. The overarching goal of this two-part investigation is to use the information gathered to improve the quality of hospital care for individuals with ASD across the lifespan.

A major takeaway from this work is that hospital providers may benefit from greater knowledge of behavioral function in hospital settings. In Study 1, participant KoBF scores below 70% for almost half of participants indicate that medical trainees and physicians do not appear to have a strong understanding of behavioral function. Further supporting this finding, many medical trainees and physicians indicated in the open-ended responses that an autism diagnosis or other mental health diagnoses are the

primary contributors to patients' severe behavior. These findings are not unique to physicians and medical trainees as BRRT personnel in Study 2 also demonstrated similar response patterns, with total KoBF scores below 70% correct for approximately 40% of participants and open-ended responses demonstrating a lack of knowledge of environmental variables that influence severe behavior. Recognizing these variables is critical for all hospital professionals who respond to patients with ASD who have a history of severe behavior. Participants indicated on open-ended and Likert scale response that they have received insufficient training on severe behavior. Similarly, during focus group discussions, BRRT personnel described the need for improved training on autism and severe behavior within BRRT teams and in general hospital providers. Prior to this investigation, the literature has focused on the need to improve physicians' general knowledge of autism. Although it is important to continually improve ASD-specific training, there is a need for specialized function-based training which could ultimately be used to improve multidisciplinary providers' response to autistic patients who engage in severe behavior.

Although medical trainees, physicians, and BRRT personnel demonstrated overall adequate knowledge of ASD and low stigma about autistic patients, this knowledge does not directly transfer to a strong understanding of behavioral function. We cannot draw conclusions about whether providers currently use function-based strategies; however, open-ended survey responses across groups often included explanations for severe behavior that were inconsistent with an understanding of environmental variables that likely contribute to these behaviors. Quantifying knowledge of behavioral function across different hospital providers is an important first step in directing future training efforts for

more compassionate and high-quality care for patients with ASD. Future research should consider quantifying knowledge of behavioral function across other types of healthcare providers, such as nurses, social workers, and security personnel, to more explicitly understand current needs.

Information gleaned from both studies may be helpful in informing the specific content of future function-based training. In terms of training curriculum, it may be important to consider the patterns of participant responses that were scored as incorrect or to which participants frequently endorsed the Don't Know response. For example, participants consistently scored lower on items related to automatic reinforcement. Understanding how severe behavior, such as self-injury, could produce its own reinforcement for the individual might be a more difficult concept to grasp. Open-ended responses across our providers described patients' diagnoses and psychiatric concerns as major contributors to severe behavior and BRRT personnel described that they are frequently called to respond to patients with a psychiatric diagnosis, underscoring the importance of teaching hospital providers to differentiate between severe behavior (e.g., self-injury) that might have an automatic function and psychiatric symptoms (e.g., hallucinations). Future training on behavioral function and compassionate care for autistic patients may include a skills-based evaluation with a competency requirement, as used in the MCPP (Bernstein et al., 2022), to ensure that knowledge translates to behavioral changes. Function-based training may ameliorate the critical gaps in hospital provider knowledge of behavioral function which can further improve care provided to autistic patients who engage in severe behavior.

Improved training initiatives across disciplines are likely to result in improved patient and provider outcomes, including fewer restraints, increased patient satisfaction, and more compassionate and effective care. Across both studies, there was converging evidence supporting the continued implementation of restraint when responding to patient severe behavior. Across hospital settings and departments, restraint is a strategy that may be used to prevent and manage hospital patient severe behavior, increase patient medical compliance (Kupzyk & Allen, 2019), and reduce staff injury (Romani et al., 2020). However, given that restraint may result in adverse consequences for the patient, provider, and caregivers (Evans et al., 2003; Salvatore et al., 2021), restraint is intended for use as a last resort after all least-restrictive interventions have been unsuccessful (American College of Emergency Physicians, 2020). Increased knowledge of behavioral function may lead to the incorporation of function-based strategies to address severe behavior more proactively. As a result, providers may be likely to replace reactive strategies like restraint, that they themselves indicate being uncomfortable facilitating, with more antecedent-based intervention strategies that prevent the occurrence of severe behavior, such as offering step-by-step descriptions of what to expect throughout an appointment when a patient has difficulty with changes in routine. As the rates of healthcare use for patients with ASD increase (Liptak et al., 2009), there is a critical need for hospital providers to be better equipped with the knowledge and competencies required to adequately work with this patient population as opposed to relying on more invasive management techniques.

Building multidisciplinary provider knowledge of behavioral function is also likely to improve provider outcomes. Our study findings highlight that function-based

training is a specialized and critical area of need and many of our participants reported that they have not received sufficient training and preparation in this area. Further, although focus group participants described a strength of BRRT teams to be their collaborative approach, they also reported frustration with the lack of knowledge of other hospital providers and misalignment of calls with need. These findings highlight why it's important for function-based training to be directed toward both BRRT team members and other hospital providers to promote a more collaborative and unified approach to treating autistic patients. The incorporation of function-based training may decrease the time spent treating neurodivergent patients who engage in unsafe and interfering behavior. Previous studies have shared that healthcare providers view treating autistic patients as more time-consuming and requiring additional resources (Mazurek et al., 2020). Function-based training may result in an increased use of function-based strategies which have the potential to decrease appointment duration. There is also a field of research investigating the high number of worker compensation claims for hospital providers, which may decrease with improved training and understanding of environmental variables contributing to and maintaining severe behavior. It must be noted, however, that function-based training efforts require buy-in from hospital administrators and providers alike, who undergo years of education and training, such that it isn't viewed as another competency-based item to add to medical curriculum and hospital trainings. One potential suggestion to ameliorate provider concerns when recommending additional training is to explore training format. The suggested training program may be self-directed such that providers can learn at their own pace and revisit

unfamiliar concepts as needed within the comfort of their home, rather than adding another in-person didactic training.

Specific elements that would be important to consider when constructing a function-based training program include incorporating the perspectives of neurodivergent individuals. Prior training programs aimed at improving hospital provider knowledge and strategies for addressing aggressive behavior have incorporated a trained neurotypical actor (e.g., Mitchell et al., 2020). A future function-based training may consider having individuals with an actual ASD diagnosis portray severe behavior, which could ultimately result in a more realistic training experience. Another important extension of Mitchell et al. (2020) that should be considered in a future function-based training is simulating other common topographies of severe behavior in hospital settings in addition to aggression, which could result in improved physician knowledge, practical skills, comfort, and competency in responding to severe behavior. Such a training has the potential to increase hospital provider function-based knowledge and ultimately decrease adverse patient outcomes, including restraint, injury, distress, and distrust in medical professionals. Future research may be conducted to examine the impact of function-based strategies and a collaborative care model on patient and provider outcomes.

This investigation generates several avenues for future research. A logical next step in this line of research includes applying our study findings to the development of an interactive training aimed at targeting hospital provider knowledge of behavioral function. Based on our findings, this function-based training should not be limited to specific types of hospital providers; rather, any multidisciplinary provider who is likely to interact with neurodivergent patients would benefit. Further, such a training program is

not restricted to those working in a hospital setting. Healthcare professionals across settings may benefit from increased understanding of behavioral function given that autistic individuals present across environments. The KoBF measure developed in this study could be used to measure recipients' knowledge following function-based training. The KoBF survey could be broadly incorporated before and after function-based training to assess knowledge of behavioral function as a pre- and post-measure. There are several existing measures, such as the QABF (Paclawskyj et al., 2000) and MAS (Durand & Crimmins, 1988) that attempt to hypothesize behavioral function for a specific individual; however, the current study developed a measure that is readily able to quantify provider knowledge of behavioral function across stages of training. Future research on this measure is critical to identify its psychometric properties and its utility for different purposes.

Given that our study did not directly examine the use of function-based strategies, we were not able to determine whether there is a correlation between function-based knowledge and the implementation of function-based strategies. Although BRRT personnel described individualized, evidence-based strategies when responding to the general patient population and autistic patients, they demonstrated low knowledge on the KoBF and described implementation of intrusive behavior management strategies such as restraint. Future research should examine the correlation between knowledge of behavioral function, as measured by the KoBF, and provider implementation of effective strategies when interacting with autistic patients who have a history of severe behavior. In future research, it may be interesting to examine the impact of hospital type and status on function-based knowledge and practice as hospitals with a teaching status, for



instance, may have dedicated efforts to train providers compared to community-based hospitals or have more specialized teams, like BRRT, that assist in responding to emergent behavior. Taken together, greater understanding of variables that impact and predict implementation of function-based strategies may be used to direct future training efforts.

The broader goal of this two-part investigation is to identify ways to improve access to high quality medical care to meet the unique needs of autistic patients who engage in severe behavior. Quantifying multidisciplinary provider knowledge of ASD and knowledge of behavioral function are important as they will shape future training efforts. These study results provide several starting points for hospitals and medical programs to serve their ever-growing population of patients with autism who may engage in severe behavior. The quantitative and qualitative information gleaned from this study suggest the need to improve the quality of care for autistic hospital patients across the lifespan.

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## Appendix A

### Tables

**Table A1**

*Physician KoBF Expert Review Revisions*

Expert Review Group	Item Clarity	Item Organization	Item Addition	Total Revisions
1	21	4	6	31
2	35	0	0	35
3	3	0	0	3
4	11	2	0	11
5	4	0	0	4

*Note.* KoBF = Knowledge of Behavioral Function; Expert Review Group 1 = Board certified behavior analysts, Group 2 = Behavior technicians, Group 3 = Psychologists, Group 4 = Individuals with ASD and caregivers, Group 5 = Medical trainees and physicians.

**Table A2**

*Study 1 Participant Demographics*

Demographic Variable	<i>n</i>	%
Gender		
Male	77	55.40
Female	61	43.89
Other	1	0.71
Ethnicity		
White	74	53.24
Asian	30	21.58
Black or African American	12	8.64
Hispanic or Latino	11	7.91
Native, Hawaiian or Pacific Islander	0	0

Demographic Variable	<i>n</i>	%
Other	12	8.63
Role		
Attending physician	50	33.33
Medical student	47	31.34
Resident	44	29.33
Fellow	9	6.00
Discipline+		
Emergency medicine	24	16.11
Internal medicine	17	11.41
Pediatrics	16	10.74
Family medicine	12	8.05
Psychiatry	15	10.10
Neurology	5	3.36
Radiology	3	2.01
Surgery	3	2.01
Other <sup>1</sup>	51	34.23
Credentials*		
M.D.: Doctor of medicine	36	73.08
D.O.: Doctor of osteopathic medicine	13	25.00
Ph.D.: Doctor of philosophy	1	1.93
Other	0	0
Years of Experience*		
Less than 5	7	13.46
6-10	12	23.08
11-15	13	25.00
16+	20	38.46

*Note.* *N* = 150; \* = attending physician demographic items only; + = discipline for

medical students included training rotations completed (e.g., “multiple” or “some of the above”). <sup>1</sup> Other responses provided by participants included pediatric critical care, critical care, urology, intensive care (groups of 2 or smaller).

**Table A3***Study 1 Endorsed Topographies of Severe Behavior.*

Topography	Percentage
Self-injury	93.33
Threatening oneself or others	91.33
Aggression	89.33
Property destruction	88.67
Suicidal/homicidal ideation	77.33
Screaming/yelling	60.00
Running away	40.00
Auditory/visual hallucinations	36.67
Repetitive motor movements	14.00
Non-compliance with medical procedure/examination	11.33
Repetitive statements	9.33

**Table A4***Study 1 KoBF Percent Correct by Category*

Category	Percentage
Positive versus negative reinforcement	87.00
Function-based intervention	77.71
Behavior maintains over time	73.78
Automatic vs. socially-mediated	72.00
Assessment of function	71.73
Environment influences behavior	69.44
Socially-mediated negative reinforcement	66.44
Reinforcement maintains behavior	59.03
Automatic negative reinforcement	59.67
Socially-mediated negative reinforcement	50.93
Automatic positive reinforcement	42.00

*Note.* KoBF = Knowledge of Behavioral Function

**Table A5***Study 1 Open-Ended Item Theme Salience by Frequency*

Theme	Vignette 1		Vignette 2		Vignette 3		Vignette 4	
	<i>f</i>	%	<i>f</i>	%	<i>f</i>	%	<i>f</i>	%
1	56	27.18	95	54.91	100	60.24	86	50.29
2	43	20.87	16	9.25	18	10.84	31	18.13
3	21	10.19	13	7.51	17	10.24	25	14.62
4	15	7.28	11	6.36	7	4.22	8	4.68
5	14	6.80	10	5.78	6	3.61	8	4.68
6	13	6.31	8	4.62	5	3.01	6	3.51
7	12	5.83	8	4.62	4	2.41	5	2.92
8	11	5.34	8	4.62	3	1.81	2	1.17
9	10	4.85	3	1.73	3	1.81	N/A	N/A
10	6	2.91	1	0.58	3	1.81	N/A	N/A
11	5	2.43	N/A	N/A	N/A	N/A	N/A	N/A

*Note.* *f* = frequency of mention; N/A indicates that no additional theme emerged for that vignette. Themes were different for each vignette.

**Table A6***Study 1 Percentage of Vignette Responses Scored Correct and Partially Correct*

Vignette	Correct	Partially Correct
1	9.87	1.32
2	14.57	13.25
3	14.67	33.33
4	6.67	12.00



**Table A7***Study 1 Examples of Correct and Partially Correct Responses by Vignette*

Vignette	Correct	Partially Correct
1	Receiving acknowledgment from the nurse after the first behavior	Wanting a person to come to the room
2	Patient wants to hold the stethoscope again	Desire for stethoscope
3	The patient does not like to be touched and is behaving the same way to prevent being touched in the future	He does not like being touched
4	Patient is able to avoid the appointment with severe behavior	Desire to avoid MRI

*Note.* MRI = magnetic resonance imaging

**Table A8***Study 1 Optional Likert-Scale Item Responses*

Likert-Scale Rating	Strongly Agree	Agree	Somewhat Agree	Disagree	Strongly Disagree
Feel discouraged by severe behavior	17.12	34.93	31.51	11.64	2.74
Restraint when unsafe/uncomfortable	8.16	36.05	29.25	17.69	6.12
Comfort with restraint for general patients	6.67	11.33	24.00	43.33	10.67
Comfort with restraint for autistic patients	4.76	22.45	28.57	32.65	9.52
Sufficient Training	3.40	8.84	14.97	41.50	29.93

*Note.* Please see Appendix C for the survey questions in full.

**Table A9***Study 2 Participant Demographics*

Demographic Variable	<i>n</i>	%
Gender		
Male	4	36.00
Female	7	64.00
Ethnicity		
White	6	54.55
Black or African American	5	45.45
Geographic Region		
Southeast	5	45.45
Midwest	3	27.27
Northeast	2	18.18
West	1	9.09
Southwest	0	0
Type of Hospital		
Teaching	10	90.91
Non-teaching	1	9.09

**Table A10***Study 2 Focus Groups Theme Descriptions Ranked by Salience*

Theme	Description
1	Various alternative strategies to restraint are implemented by BRRT across patient populations.
2	The purpose and procedures of BRRT vary by hospital.
3	There are several indicated weaknesses of BRRT and potential areas for improvement.
4	Hospitals have specific debrief and documentation processes after BRRT call.
5	Hospitals have differences in BRRT training across personnel and differences in team membership credentials.
6	Hospital characteristics influence BRRT response.
7	Restraint is used to manage severe behavior.
8	Perceived knowledge deficits and negative perceptions influence BRRT call.
9	Alternative strategies are used for patients with ASD who engage in severe behavior.
10	Interpersonal characteristics influence BRRT response.
11	Patient mental or behavioral health influence BRRT call.

*Note.* BRRT = behavioral rapid response team; ASD = autism spectrum disorder

**Table A11***Frequency and Percentage of Themes Mentioned*

Theme	<i>f</i>	%
Theme 1	61	15.28
Theme 1a	18	29.51
Theme 1b	15	24.59
Theme 1c	15	24.59
Theme 1d	10	16.39
Theme 1e	3	4.92
Theme 2	58	14.53
Theme 2a	21	36.21
Theme 2b	17	29.31
Theme 2c	14	24.14
Theme 2d	6	10.34
Theme 3	50	12.53
Theme 3a	19	38.00
Theme 3b	17	34.00
Theme 3c	7	14.00
Theme 3d	7	14.00
Theme 4	39	9.77
Theme 4a	15	38.46
Theme 4b	11	28.21
Theme 4c	8	20.51
Theme 4d	5	12.82
Theme 5	38	9.52
Theme 5a	17	44.74
Theme 5b	9	23.68
Theme 5c	8	21.05
Theme 5d	4	10.53
Theme 6	38	9.52
Theme 6a	22	57.89
Theme 6b	10	26.32
Theme 6c	6	15.79
Theme 7	31	7.77
Theme 7a	14	45.16
Theme 7b	7	22.58
Theme 7c	5	16.13
Theme 7d	5	16.13

Theme	<i>f</i>	%
Theme 8	27	6.78
Theme 8a	17	62.96
Theme 8b	10	37.04
Theme 9	27	6.78
Theme 9a	10	37.04
Theme 9b	7	25.93
Theme 9c	6	22.22
Theme 9d	4	14.81
Theme 10	16	4.01
Theme 10a	8	50.00
Theme 10b	8	50.00
Theme 11	14	3.51

*Note.* BRRT = behavioral rapid response team; *f* = frequency of mention; ASD = autism spectrum disorder

**Table A12**

*Study 2 Themes Mentioned by Lines of Transcript*

Theme	Total Lines
Theme 1	47
Theme 2	54
Theme 3	47
Theme 4	36
Theme 5	36
Theme 6	37
Theme 7	24.5
Theme 8	23
Theme 9	26

Theme	Total Lines
Theme 10	14
Theme 11	7

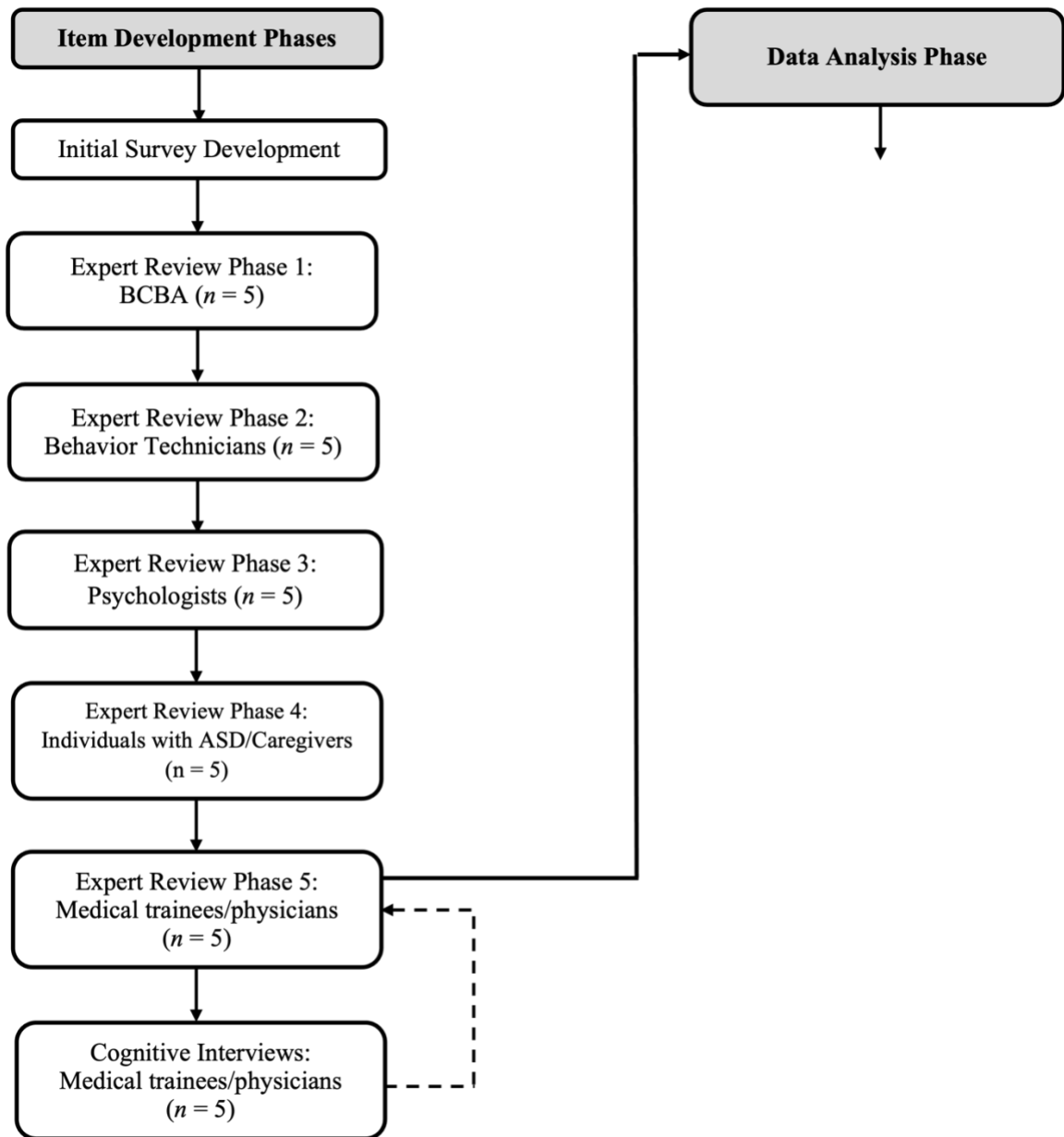
*Note.* BRRT = behavioral rapid response team

## Appendix B

### Figures

**Figure B1**

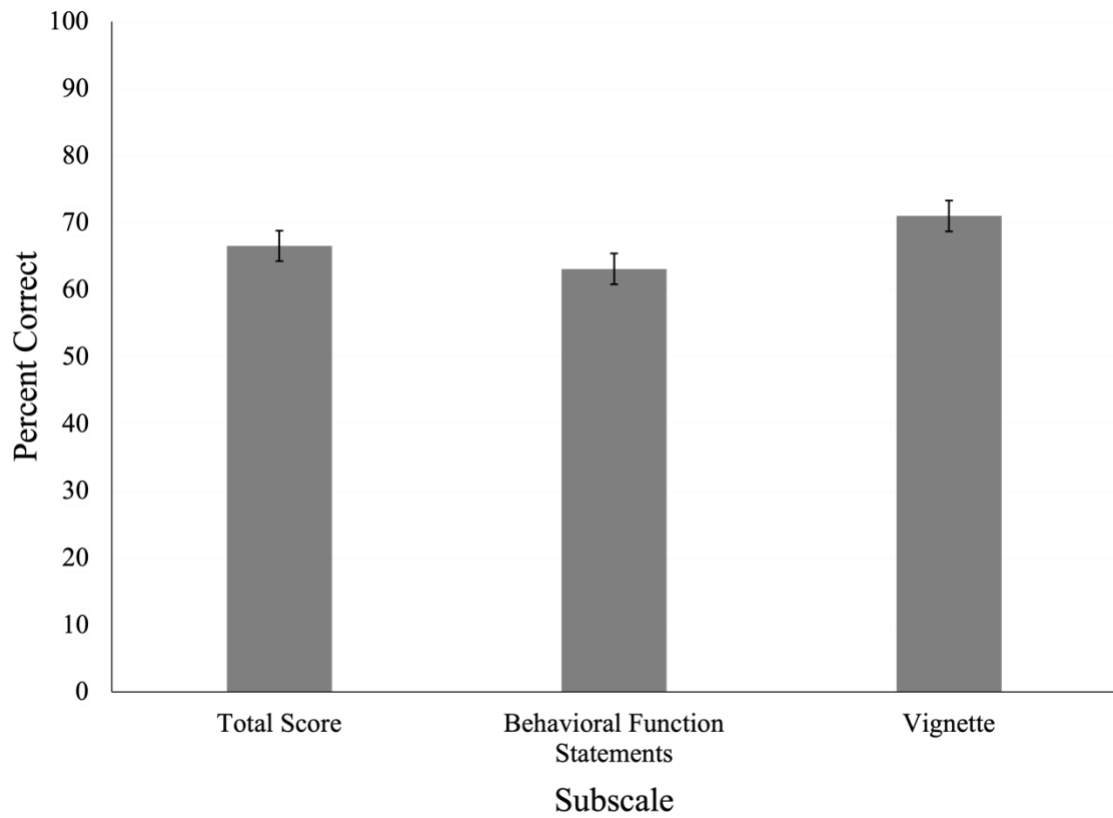
*KoBF Survey Development Across Item Development and Data Analysis*



*Note.* KoBF = Knowledge of Behavioral Function; BCBA = board certified behavior analyst; ASD = autism spectrum disorder

**Figure B2**

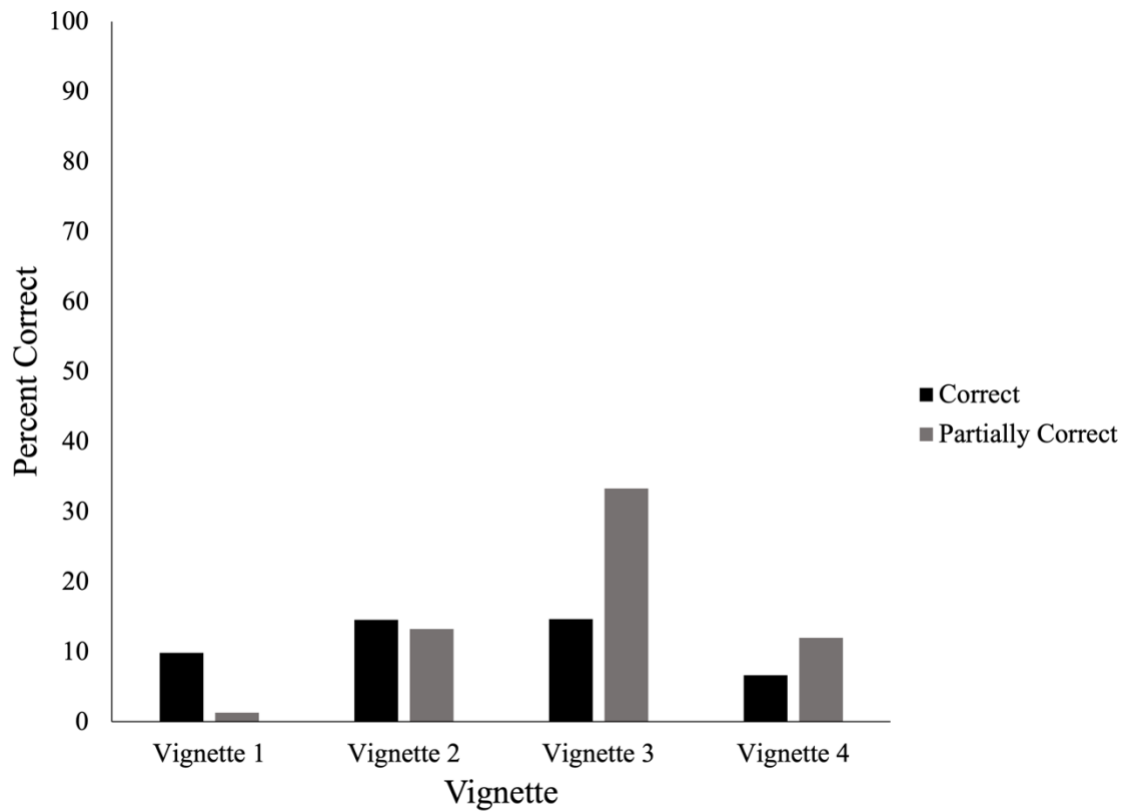
*Study 1 KoBF Mean Percent Correct by Subscale*



*Note.* KoBF = Knowledge of Behavioral Function

**Figure B3**

*Study 1 KoBF Mean Percent Correct and Partially Correct Responses by Vignette*

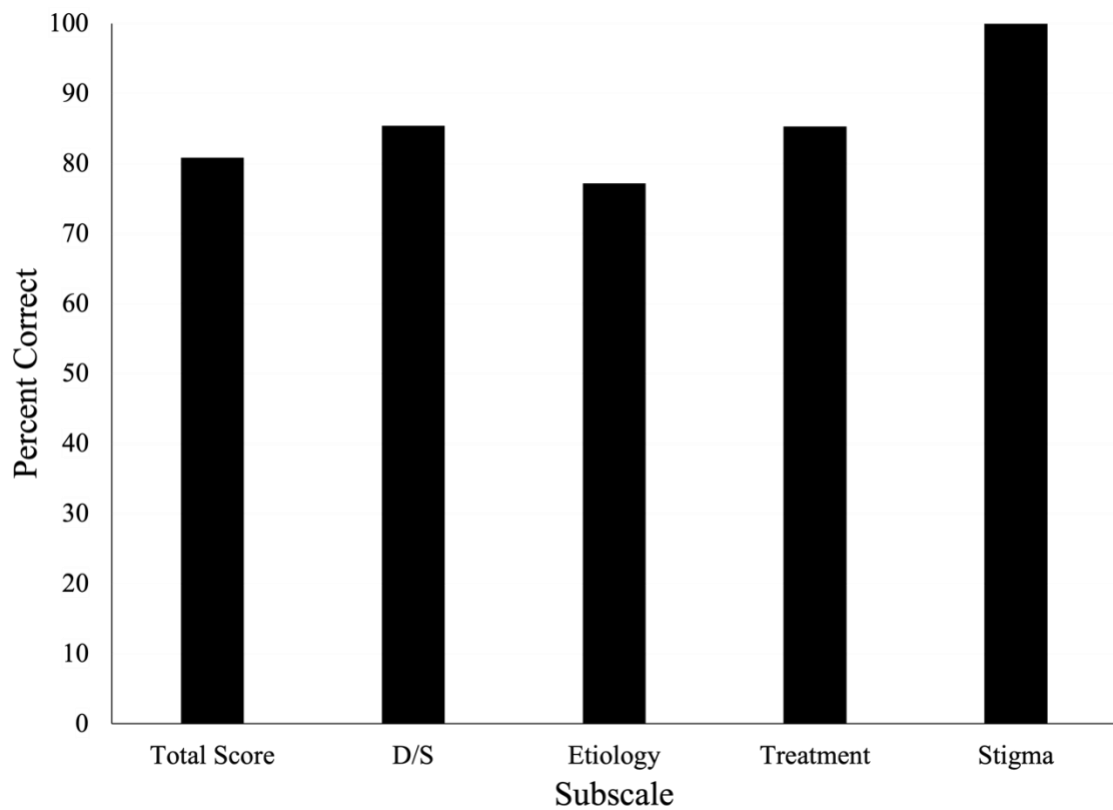


*Note. KoBF = Physician Knowledge of Behavioral Function*



**Figure B4**

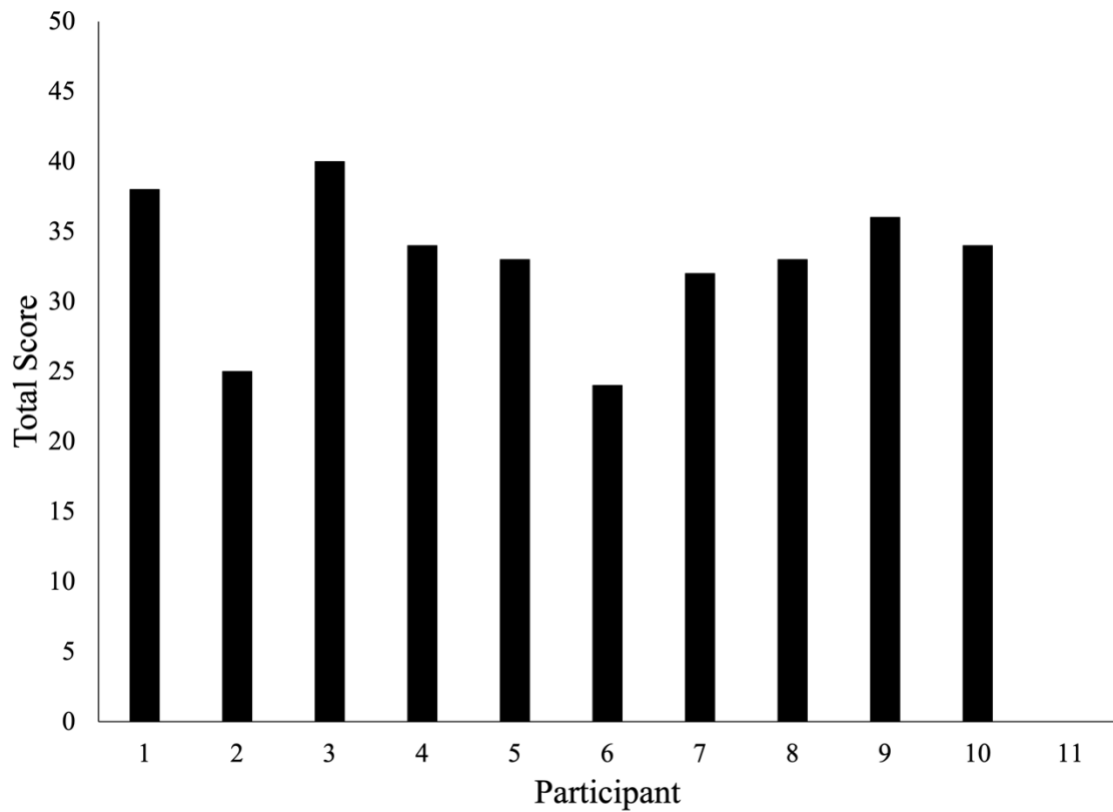
*Study 1 ASK-Q Percent Correct by Subscale*



*Note.* ASK-Q = Physician Autism Stigma and Knowledge Questionnaire; D/S indicates Diagnosis/Symptoms subscale. Stigma is reverse scored such that a score of 100% indicates no instances of stigma endorsed.

**Figure B5**

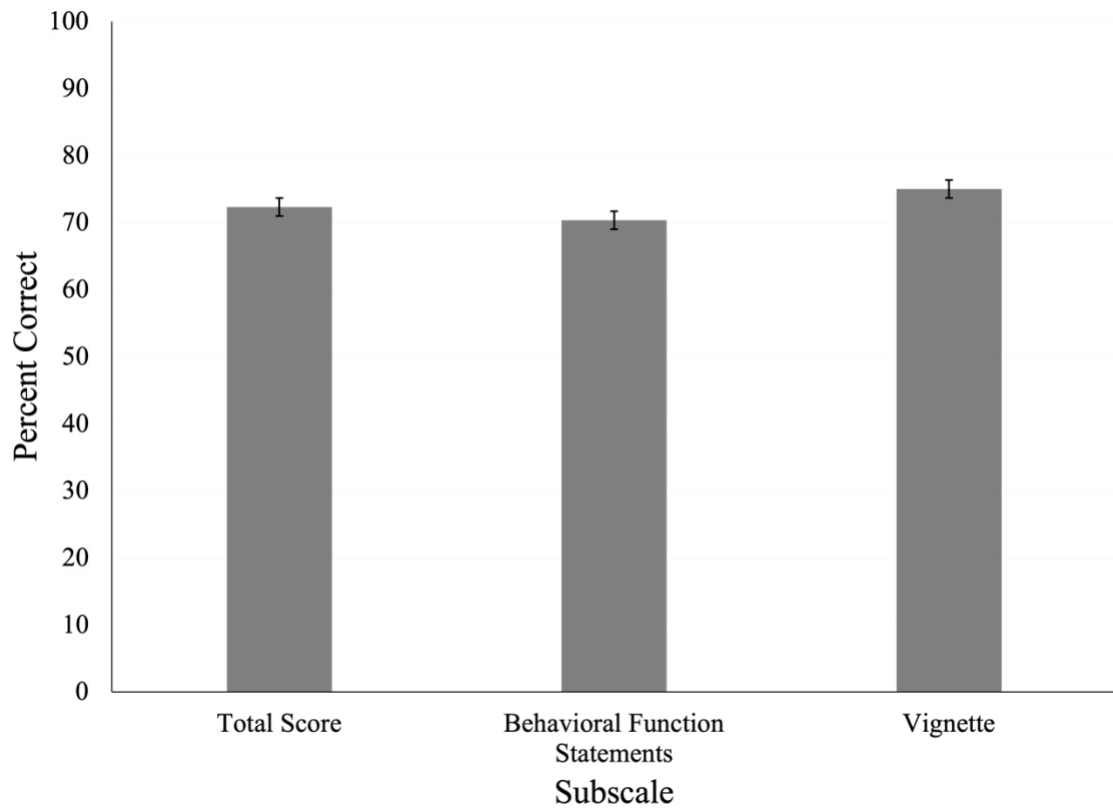
*Study 2 KoBF Scores by Participant*



*Note.* KoBF = Knowledge of Behavioral Function; Participant 11 did not complete the survey.

**Figure B6**

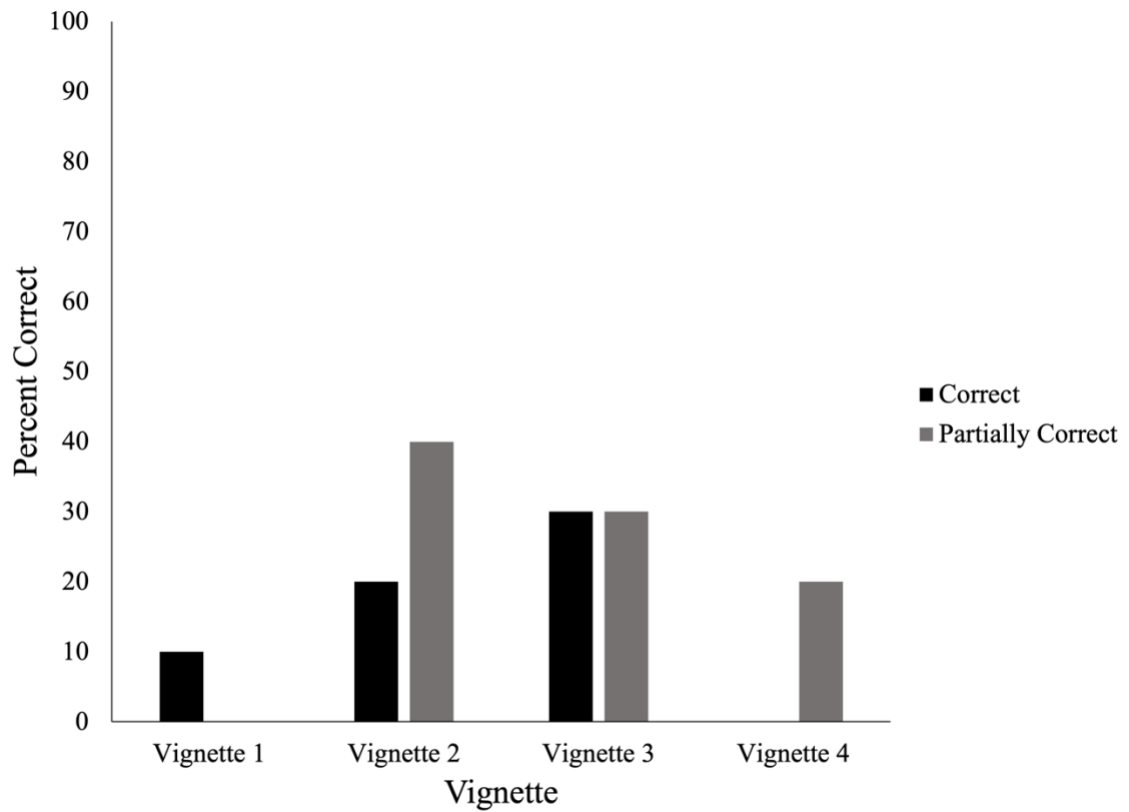
*Study 2 KoBF Percent Correct by Subscale*



*Note.* KoBF = Knowledge of Behavioral Function

**Figure B7**

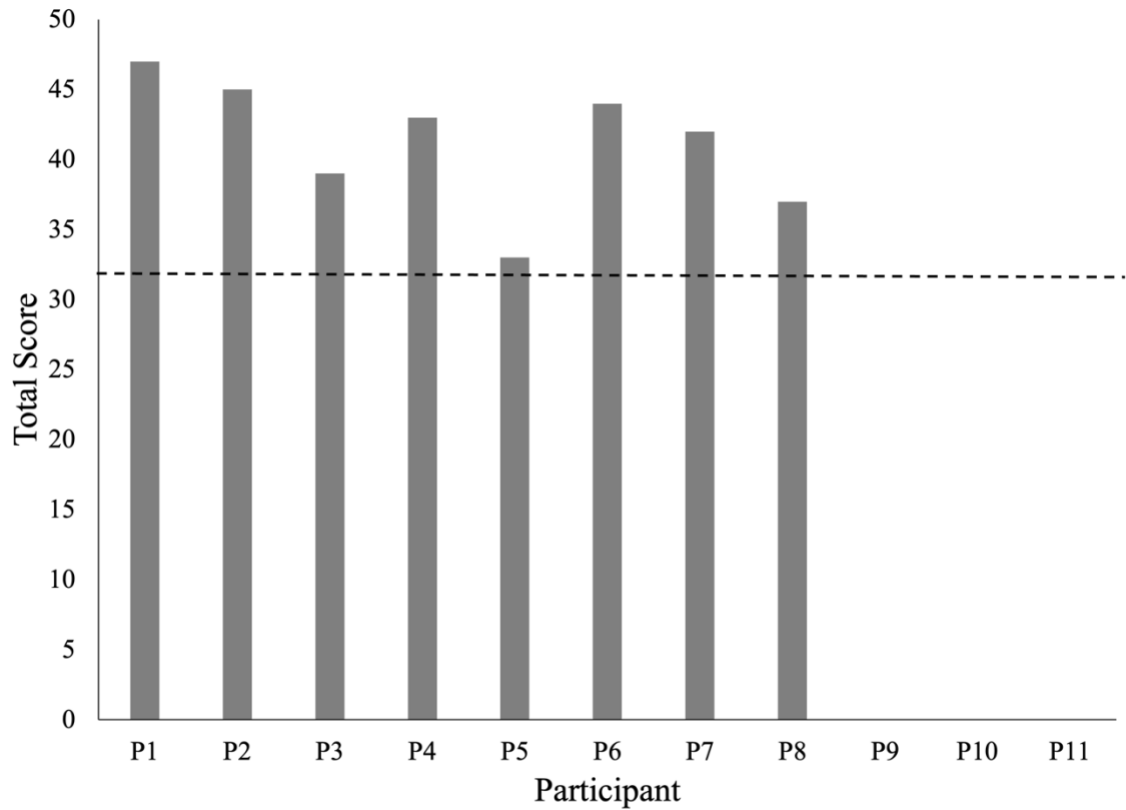
*Study 2 KoBF Mean Percent Correct and Partially Correct Responses by Vignette*



*Note. KoBF = Physician Knowledge of Behavioral Function*

**Figure B8**

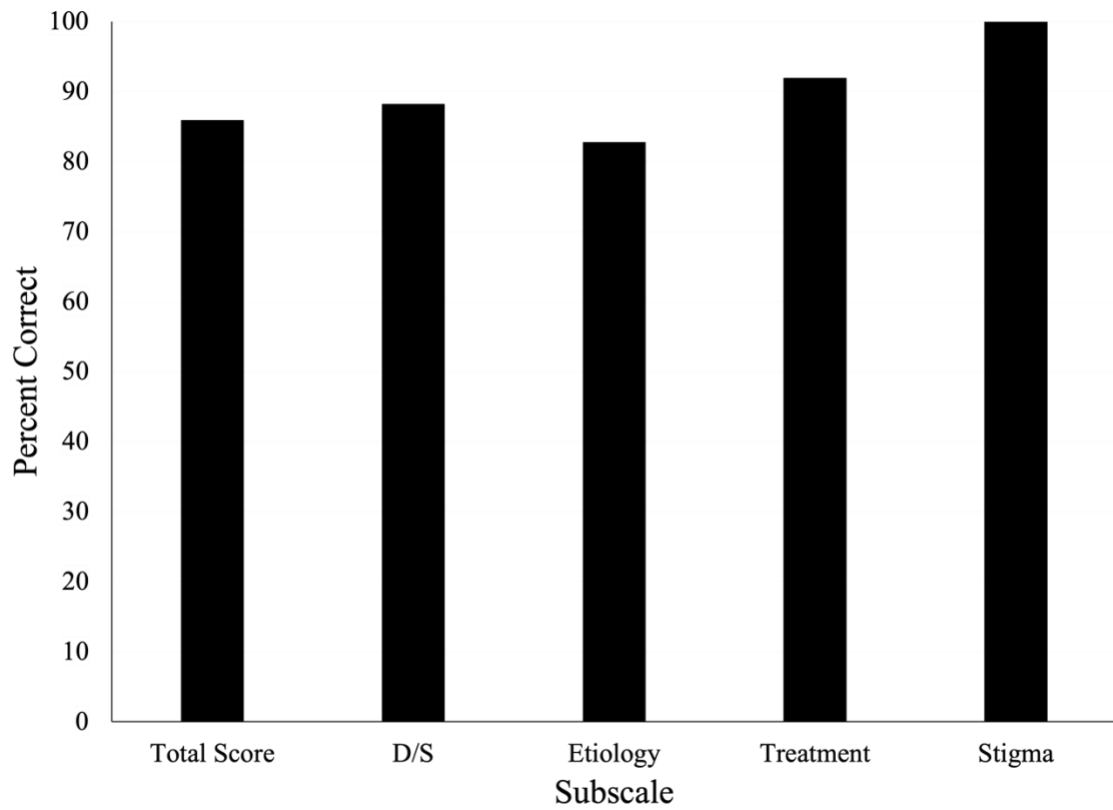
*Study 2 ASK-Q Scores by Participant*



*Note.* ASK-Q = Physician Autism Stigma and Knowledge Questionnaire; Participants 9-11 did not complete the survey. The adequate total score cutoff of 32 (minimum correct in each subscale) is indicated by the dashed line.

**Figure B9**

*Study 2 ASK-Q Percent Correct by Subscale*



*Note.* ASK-Q = Physician Autism Stigma and Knowledge Questionnaire; D/S indicates Diagnosis/Symptoms subscale; Stigma subscale is reverse scored such that 100% correct is indicative of no stigma endorsed.

## Appendix C

### Study 1: Knowledge of Behavioral Function Survey

#### Instructions

You are invited to participate in this online research survey titled Understanding Hospital Patient Severe Behavior. To participate in this survey, you must be a physician or medical trainee (i.e., medical student, fellow, resident) in one of the following target hospital departments: Emergency Medicine, Neurology, Pediatrics, Psychiatry.

This survey will take no more than 10 minutes to complete. Your participation is voluntary. If you do not wish to participate, do not respond to this survey. Completing this survey indicates that you are voluntarily giving consent to participate in the survey.

The purpose of this study is to determine the standard of care for treating patients with autism across the lifespan in hospital settings (e.g., emergency room visit, admitted sick patient, outpatient procedure, inpatient), and to identify staff needs.

**Throughout this survey, we will refer to individuals with autism spectrum disorder as “patients with autism”. We are using this terminology to be consistent across this survey and to align with the Diagnostic and Statistical Manual of Mental Disorders, 5<sup>th</sup> Edition, Text Revision (DSM-5; American Psychological Association, 2022). We shortened the term “autism spectrum disorder” to refer colloquially to “autism”. We recognize that patients may prefer to be referred to as autistic or by other terms. We believe that patients should be referred to using their preferred terms.**

**We will also use the term “severe behavior” throughout the survey as it is used in medical and behavioral literature. In using this term, we are attempting to describe a broad category of behavior rather than the individual but recognize that certain terms may be viewed as stigmatizing.**

There are minimal risks associated with this survey. You may experience momentary discomfort in answering survey items. There may be no direct benefit to you, however, by participating in this study, you may assist us in learning how to best support healthcare providers and hospital patients with autism. Following study participation, you will be entered into a random drawing for a \$75 online gift card.

Your response will be kept confidential. We will store the data in a secure computer file and the file will be destroyed once the data have been published. Any part of the research related to your participation that is published will not include your individual information. If you have any questions about the survey, you can contact Dr. Christina Simmons, the Principal Investigator, at the address provided below, but you do not have to give your personal identification.

Dr. Christina Simmons

simmonsc@rowan.edu  
Rowan University  
201 Mullica Hill Rd  
Glassboro, NJ 08028

If you have any questions about your rights as a research subject, please contact the Office of Research Compliance at (856) 256-4078– Glassboro/CMSRU. This study has been approved by the Rowan IRB, PRO-2021-703

### **Demographics**

1. Gender
  - Male
  - Female
  - Other: \_\_\_\_\_
2. Ethnicity
  - White
  - Hispanic or Latino
  - Black or African American
  - Asian
  - American Indian or Alaska Native
  - Native Hawaiian or Other Pacific Islander
  - Other: \_\_\_\_\_
3. Select your current role(s)
  - Attending physician
  - Behavioral rapid response/related team member
  - Fellow
  - Resident
  - Medical student



- Other: \_\_\_\_\_
4. Select your behavioral rapid response or related team role (route for FG participants only)
- Nurse/nurse practitioner
  - Physician
  - Security/police
  - Social worker/case manager
  - Other: \_\_\_\_\_
5. Select your current training year (route for med students/residents/fellows only)
- First
  - Second
  - Third
  - Fourth
  - Other: \_\_\_\_\_
6. Years of experience (route for attendings only)
- Less than 5
  - 6-10
  - 11-15
  - 15+
7. Select your primary department (route for physicians/residents/fellows only) or  
Select your current rotation (route for students only)
- Emergency medicine
  - Neurology

- Pediatrics
  - Psychiatry
  - Other: \_\_\_\_\_
8. Select rotations completed (route for students only)
- Emergency medicine
  - Neurology
  - Pediatrics
  - Psychiatry
  - Other: \_\_\_\_\_
9. Select your credential(s) (route for physicians/residents/fellows)
- D.O.: Doctor of osteopathic medicine
  - M.D.: Doctor of medicine
  - Ph.D.: Doctor of philosophy
  - Other: \_\_\_\_\_
10. Select the credential(s) you're pursuing (route for students)
- D.O.: Doctor of osteopathic medicine
  - M.D.: Doctor of medicine
  - Ph.D.: Doctor of philosophy
  - Other: \_\_\_\_\_
11. Check all that apply. In my opinion, I consider severe behavior to include the following occurrences or attempts:
- Aggression
  - Auditory/visual hallucinations

- Non-compliance with medical procedure or examination
- Property destruction
- Repetitive motor movements (e.g., hand flapping, body rocking)
- Repetitive statements (e.g., echoing lines from media)
- Running away
- Screaming/yelling
- Self-injury
- Suicidal/homicidal ideation
- Threatening oneself or others
- Other: \_\_\_\_\_

*Behavioral Function True or False Questions*

For the remaining survey items, severe behavior in the hospital setting includes any of the following: attempting to/or running away, screaming/yelling, threatening themselves or others, aggression, self-injurious behavior, and/or property destruction.

12. Patients with autism may engage in severe behavior to alleviate pain or discomfort.

- True
- False
- Don't know

13. Patients with autism are unlikely to engage in severe behavior again when they return to the hospital and encounter a similar scenario.

- True
  - False
  - Don't know
14. Patients with autism only engage in severe behavior when in the presence of others.
- True
  - False
  - Don't know
15. Patients with autism are unlikely to engage in severe behavior because of the sensation they experience while in an environment without things they find engaging.
- True
  - False
  - Don't know
16. Patients with autism almost always engage in severe behavior to get a reaction from others.
- True
  - False
  - Don't know
17. Patients with autism may engage in severe behavior to reach an internal state of peace.
- True
  - False
  - Don't know

18. Patients with autism almost always engage in severe behavior because they can't help it or control their behavior.

- True
- False
- Don't know

19. Patients with autism are unlikely to engage in severe behavior during hospital visits to communicate to hospital staff that they are in pain.

- True
- False
- Don't know

20. Patients with autism may engage in severe behavior because it results in verbal reprimands from others.

- True
- False
- Don't know

21. Patients with autism only engage in severe behavior to get something they want.

- True
- False
- Don't know

22. Patients with autism may engage in severe behavior to receive attention from others around them.

- True
- False

- Don't know
23. Severe behavior in patients with autism's reason for occurrence can only be confirmed by looking at the pattern of behavior over time.
- True
  - False
  - Don't know
24. Patients with autism may engage in severe behavior because it feels good to them.
- True
  - False
  - Don't know
25. Patients with autism only engage in severe behavior to get out of doing something.
- True
  - False
  - Don't know
26. Patients with autism may engage in severe behavior to seek an unpleasant or uncomfortable feeling.
- True
  - False
  - Don't know
27. Patients with autism may engage in severe behavior to avoid or terminate conversation or social interaction.

- True
  - False
  - Don't know
28. Patients with autism may engage in severe behavior when no one is around them.
- True
  - False
  - Don't know
29. Severe behavior in patients with autism is unlikely to be changed with behavioral intervention implemented by themselves or others.
- True
  - False
  - Don't know
30. Severe behavior in patients with autism almost always occurs because of their autism.
- True
  - False
  - Don't know
31. Severe behavior in patients with autism can almost always be explained by what occurs after the behavior.
- True
  - False
  - Don't know

32. Severe behavior in patients with autism only occurs because it results in termination or avoidance of physical touch.
- True
  - False
  - Don't know
33. Severe behavior in patients with autism is unlikely to be prevented by hospital staff through behavioral interventions.
- True
  - False
  - Don't know
34. Severe behavior in patients with autism may be preceded by clear triggers.
- True
  - False
  - Don't know
35. Severe behavior in patients with autism may occur again when they return to the hospital and encounter similar circumstances.
- True
  - False
  - Don't know
36. Severe behavior in patients with autism will almost always stop or not occur in the future if they are verbally reprimanded.
- True
  - False



- Don't know
- 37. Severe behavior in patients with autism almost always occurs for a reason.
  - True
  - False
  - Don't know
- 38. Severe behavior in patients with autism is unlikely to occur because they intend to harm someone or something.
  - True
  - False
  - Don't know

### *Vignette Questions*

For the vignette items that follow, please refer to the corresponding vignette when answering each question.

#### *Vignette 1*

During a medical appointment while the patient is waiting in the examination room, the patient bangs their hands against the wall and makes unusual sounds. When a nurse enters the room, the nurse attempts to verbally de-escalate the patient by making statements such as, "Please calm down." During future medical appointments, the patient bangs their hands against the wall.

39. What do you think is causing this patient's severe behavior?

\_\_\_\_\_

40. There is no way to evaluate why this patient's severe behavior is occurring.

- ☐ True
- ☐ False
- ☐ Don't know

41. This patient's severe behavior has nothing to do with what is happening in the environment.

- ☐ True
- ☐ False
- ☐ Don't know

42. The hospital staff's response may contribute to this patient's severe behavior occurring again.

- ☐ True
- ☐ False
- ☐ Don't know

43. There is nothing hospital staff could do to prevent this patient's severe behavior from occurring again.

- ☐ True
- ☐ False
- ☐ Don't know

44. This patient's severe behavior is most likely occurring due to the desire to avoid or terminate the medical appointment.

- ☐ True
- ☐ False
- ☐ Don't know

*Vignette 2*

During an appointment, the patient reaches for a physician's stethoscope. When the physician removes the stethoscope from the patient's hands, the patient curses loudly and throws a chair in the direction of the physician. The stethoscope falls off the physician and the patient picks up the stethoscope and holds it while the appointment continues as usual. During future appointments, the patient immediately begins cursing and throwing items when the physician enters the room.

45. What do you think is causing this patient's severe behavior?

\_\_\_\_\_

46. There are ways to evaluate why this patient's severe behavior is occurring.

- ☐ True
- ☐ False
- ☐ Don't know

47. This patient's severe behavior is not due to what is happening in the physical environment.

- ☐ True

- False
  - Don't know
48. The hospital staff cannot predict when this patient's severe behavior will occur during future medical appointments.
- True
  - False
  - Don't know
49. The hospital staff could decrease the likelihood of this patient's severe behavior from occurring again in the future.
- True
  - False
  - Don't know
50. This patient's severe behavior is most likely occurring to access the stethoscope.
- True
  - False
  - Don't know

### *Vignette 3*

During an appointment, a physician is conducting a physical examination for concerns related to the patient's stomach. When the physician touches the patient's forehead to take their temperature, the patient pushes the physician and spits in their direction. The physician immediately steps back from the patient and asks the patient questions about

their symptoms for the rest of the appointment. During future medical appointments, the patient starts to push and spit as soon as hospital staff begin to take their vital signs.

51. What do you think is causing this patient's severe behavior?

\_\_\_\_\_

52. It is possible to identify why this patient's severe behavior is occurring.

- True
- False
- Don't know

53. The physical environment must be considered when assessing why this patient's severe behavior is occurring.

- True
- False
- Don't know

54. The physician's response is likely contributing to this patient's severe behavior occurring again during future medical appointments.

- True
- False
- Don't know

55. There is no change in physician behavior that can prevent this patient's severe behavior from occurring again during future medical appointments.

- True
- False

- Don't know
56. The patient's severe behavior is most likely occurring because of their stomach pain.
- True
  - False
  - Don't know

*Vignette 4*

During a regularly scheduled MRI, the patient runs out of the room while yelling. When the technicians ask the patient to return to the room, the patient does not comply and the procedure needs to be rescheduled. During future medical appointments, the patient's severe behavior escalates to more severe types of behavior, including placing hospital staff in a headlock and punching a nearby patient.

57. What do you think is causing this patient's severe behavior?
- \_\_\_\_\_

58. There is no way to evaluate why this patient's severe behavior is occurring across settings.
- True
  - False
  - Don't know
59. Environmental factors may contribute to this patient's severe behavior.
- True

- False
  - Don't know
- 60. The hospital staff's response may be increasing the future likelihood of this patient's severe behavior.
  - True
  - False
  - Don't know
- 61. A change in hospital staff behavior could prevent this patient's severe behavior from occurring again in the future.
  - True
  - False
  - Don't know
- 62. This patient's severe behavior is most likely occurring to avoid or get out of the procedure.
  - True
  - False
  - Don't know

### *Optional Questions*

For the remaining survey items, restraint in the hospital setting includes any of the following interventions implemented to proactively or reactively manage severe behavior: physical (i.e., hold or transport), mechanical (i.e., device or equipment), or chemical (i.e., pharmacological) intervention. According to the medical and behavioral

literature, restraint should only be used after all less-restrictive interventions have been exhausted and there is an immediate safety concern.

63. I feel discouraged when patients engage in severe behavior during their hospital stay.

- Strongly agree
- Agree
- Somewhat agree
- Disagree
- Strongly disagree

64. I recommend/place restraint orders when myself and/or my team feels unsafe or uncomfortable managing hospital patients' severe behavior.

- Strongly agree
- Agree
- Somewhat agree
- Disagree
- Strongly disagree

65. I am comfortable using restraint either myself or with a team to manage patients with autism's severe behavior.

- Strongly agree
- Agree
- Somewhat agree
- Disagree



- Strongly disagree
66. I am comfortable recommending/placing restraint orders to manage patients with autism who engage in severe behavior.
- Strongly agree
  - Agree
  - Somewhat agree
  - Disagree
  - Strongly disagree
67. I currently receive sufficient training to manage patients with autism who engage in severe behavior.
- Strongly agree
  - Agree
  - Somewhat agree
  - Disagree
  - Strongly disagree

## **Appendix D**

### **Study 1: KoBF Themes and Subthemes by Vignette**

#### **Vignette 1 (Attention Function)**

1. Environment is causing patient severe behavior.
2. Internal stimuli are causing patient severe behavior.
  - a) The patient has different feelings (anxiety, fear, anger, stress, nervousness)
  - b) The patient is uncomfortable.
  - c) The patient is in pain.
3. The patient seeks attention from nurses and other staff.
  - a) The patient wants attention.
  - b) The patient gets attention (score if they mention repeating similar behaviors, positive reinforcement).
4. The patient lacks skills to understand, de-escalate, or communicate.
5. The patient's autism diagnosis is causing the severe behavior.
6. The respondent did not know why the behavior was occurring or indicated a lack of training.
7. The patient has had bad past experiences with medical settings.
8. The patient is self-soothing or making themselves feel better.
9. The patient being left alone and waiting.
10. The patient is bored or understimulated.
11. Healthcare provider responded in the wrong way.

#### **Vignette 2 (Tangible Function)**

1. The stethoscope contributes to the patient's severe behavior.

- a) The behavior results in access to the stethoscope.
  - b) The patient wants to hold/get/touch stethoscope.
  - c) The patient uses the stethoscope to soothe or feel pleasure.
  - d) The healthcare provider removed the stethoscope.
2. The respondent did not know why the behavior was occurring or indicated a lack of training.
3. Physician and patient conflict as causing patient severe behavior.
- a) Healthcare provider responded in the wrong way.
  - b) The patient is angry at the physician.
  - c) The patient disagrees with the physician.
  - d) The patient wants something because it's the physician's.
  - e) The physician is asking the patient to do something they don't want to do.
  - f) The patient is afraid of the doctor.
4. The patient has had bad past experiences with medical settings and healthcare providers.
5. Patient emotions or mental states are causing patient severe behavior.
6. The patient lacks the skills to communicate or has limited coping strategies.
7. Environmental factors (not including the physician or stethoscope) are causing the patient's severe behavior.
8. The patient's autism diagnosis is causing the severe behavior.
9. The patient engages in severe behavior to get attention.
10. The patient wants to escape the appointment.

### **Vignette 3 (Escape From Physical Touch Function)**

1. The patient is attempting to escape.
  - a) The patient is attempting to escape physical touch.
  - b) The patient's severe behavior results in escape or avoidance of physical touch.
  - c) The patient is attempting to escape the appointment or scenario.
2. The respondent did not know why the behavior was occurring or indicated a lack of training.
3. The patient has different feelings (anxiety, fear/threatened, anger, stress, nervousness, disapproval, pain).
4. The patient's challenges contribute to the severe behavior.
  - a) The patient has difficulty communicating.
  - b) The patient does not comprehend the purpose of the appointment.
5. Environmental factors (not including the physician or appointment) are causing the patient's severe behavior.
6. The healthcare provider responded in the wrong way.
7. The patient is experiencing sensory overload.
8. The patient dislikes or is afraid of getting vitals taken.
9. The patient has had bad past experiences with medical settings and healthcare providers.
10. The patient's autism diagnosis is causing the severe behavior.

### **Vignette 4 (Escape From Procedure Function)**

1. The MRI is causing the patient's severe behavior.

- a) The patient is afraid, surprised, or anxious about the MRI.
  - b) The patient is attempting to escape the MRI or appointment in general.
  - c) The patient's severe behavior results in escape or avoidance of the MRI.
  - d) The patient is experiencing overstimulation from the noise of the machine.
2. The patient has different feelings (discomfort, anxiety, fear, anger, stress, nervousness, panic, frustration, pain).
  3. The respondent did not know why the behavior was occurring or indicated a lack of training.
  4. Environmental factors (not including the appointment) are causing the patient's severe behavior.
  5. The patient's autism diagnosis is causing the severe behavior.
  6. The patient lacks the skills to communicate or has limited coping strategies.
  7. The healthcare provider responded in the wrong way.
  8. The patient has had bad past experiences with medical settings and healthcare providers.

## **Appendix E**

### **Study 1: KoBF Items by Category**

#### **Reinforcement Maintains Behavior**

- Patients with autism almost always engage in severe behavior because they can't help it or control their behavior.
- Severe behavior in patients with autism almost always occurs because of their autism.
- Severe behavior in patients with autism can almost always be explained by what occurs after the behavior.
- Severe behavior in patients with autism almost always occurs for a reason.
- Severe behavior in patients with autism is unlikely to occur because they intend to harm someone or something.

#### **Behavior Maintains Over Time**

- Patients with autism are unlikely to engage in severe behavior again when they return to the hospital and encounter a similar scenario.
- Severe behavior in patients with autism may occur again when they return to the hospital and encounter similar circumstances.
- The hospital staff's response may contribute to this patient's severe behavior occurring again.
- The hospital staff cannot predict when this patient's severe behavior will occur during future medical appointments.
- The physician's response is likely contributing to this patient's severe behavior occurring again during future medical appointments.

- The hospital staff's response may be increasing the future likelihood of this patient's severe behavior.

### **Environment Influences Behavior**

- Patients with autism are unlikely to engage in severe behavior during hospital visits to communicate to hospital staff that they are in pain.
- Severe behavior in patients with autism may be preceded by clear triggers.
- This patient's severe behavior has nothing to do with what is happening in the environment.
- This patient's severe behavior is not due to what is happening in the physical environment.
- The physical environment must be considered when assessing why this patient's severe behavior is occurring.
- Environmental factors may contribute to this patient's severe behavior.

### **Positive versus Negative Reinforcement**

- Patients with autism only engage in severe behavior to get something they want.
- Patients with autism only engage in severe behavior to get out of doing something.

### **Automatic Versus Socially-mediated**

- Patients with autism only engage in severe behavior when in the presence of others.
- Patients with autism may engage in severe behavior when no one is around them.

### **Automatic Positive Reinforcement**

- Patients with autism are unlikely to engage in severe behavior because of the sensation they experience while in an environment without things they find engaging.
- Patients with autism may engage in severe behavior to reach an internal state of peace.
- Patients with autism may engage in severe behavior because it feels good to them.

### **Automatic Negative Reinforcement**

- Patients with autism may engage in severe behavior to alleviate pain or discomfort.
- Patients with autism may engage in severe behavior to seek an unpleasant or uncomfortable feeling.

### **Socially-mediated Positive Reinforcement**

- Patients with autism almost always engage in severe behavior to get a reaction from others.
- Patients with autism may engage in severe behavior because it results in verbal reprimands from others.
- Patients with autism may engage in severe behavior to receive attention from others around them.
- This patient's severe behavior is most likely occurring due to the desire to avoid or terminate the medical appointment.
- This patient's severe behavior is most likely occurring to access the stethoscope.



### **Socially-mediated Negative Reinforcement**

- Patients with autism may engage in severe behavior to avoid or terminate conversation or social interaction.
- Severe behavior in patients with autism only occurs because it results in termination or avoidance of physical touch.
- The patient's severe behavior is most likely occurring because of their stomach pain.

### **Assessment of Function**

- Severe behavior in patients with autism's reason for occurrence can only be confirmed by looking at the pattern of behavior over time.
- There is no way to evaluate why this patient's severe behavior is occurring.
- There are ways to evaluate why this patient's severe behavior is occurring.
- It is possible to identify why this patient's severe behavior is occurring.
- There is no way to evaluate why this patient's severe behavior is occurring across settings.

### **Function-based Treatment**

- Severe behavior in patients with autism is unlikely to be changed with behavioral intervention implemented by themselves or others.
- Severe behavior in patients with autism is unlikely to be prevented by hospital staff through behavioral interventions.
- Severe behavior in patients with autism will almost always stop or not occur in the future if they are verbally reprimanded

- There is nothing hospital staff could do to prevent this patient's severe behavior from occurring again.
- The hospital staff could decrease the likelihood of this patient's severe behavior from occurring again in the future.
- There is no change in physician behavior that can prevent this patient's severe behavior from occurring again during future medical appointments.
- A change in hospital staff behavior could prevent this patient's severe behavior from occurring again in the future.

## Appendix F

### Study 2: Behavioral Rapid Response Team Focus Group Guide

1. What is the purpose of behavioral rapid response teams (BRRT) at your hospital?
2. How is BRRT activated at your hospital? What does this process look like?
  - a. *Prompt: Coding system*
  - b. *Prompt: Tools/equipment/materials*
  - c. *Prompt: How many people respond?*
3. Who is typically on a BRRT at your hospital?
  - a. *Prompt: Responsibilities by personnel*
4. What credentials/training are required for BRRT membership at your hospital?
  - a. *Prompt: Training specific to autism (formal vs. informal)*
5. What are some common strategies for responding to severe behavior at your hospital?
6. Can you describe a recent BRRT response to severe behavior?
7. How would BRRT respond to severe behavior of a general hospital patient compared to a patient with autism at your hospital?
  - a. *Prompt: Variability in response by age (e.g., children vs. adults) and severe behavior type*
8. What is the process after responding to patient severe behavior at your hospital?
  - a. *Prompt: Documentation*
9. How can BRRT be improved at your hospital?
  - a. *Prompt: Training*
  - b. *Prompt: Documentation*

c. *Prompt: Protocols and coding systems*

10. How do BRRT personnel work together at your hospital?

a. *Prompt: In the moment and staff trainings*

11. Is there anything else you would like to share about responding to severe behavior for patients with autism at your hospital?