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Effectiveness of Adaptive Care Plans for Children with Developmental Disabilities During
Outpatient Clinic Appointments

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Abstract

Children with developmental disabilities have a greater number of medical diagnoses and consequently require more medical experiences than typically-developing children (Schieve et al., 2012). Healthcare providers and parents report that children with developmental disabilities exhibit problematic behaviors and struggle to cooperate with healthcare encounters (Bultas, McMillin, & Zand, 2016). Adaptive care plans are individualized patient-centered plans created to minimize the harmful effects of hospital experiences, and address the challenges that children with developmental disabilities experience during healthcare encounters (Liddle, Birkett, Bonjour, & Risma, 2018). The current study evaluated if adaptive care plans can positively affect the psychosocial outcomes among children with developmental disabilities, and greater parent and medical personnel satisfaction with the healthcare visit, compared to children with developmental disabilities who do not have adaptive care plans. One-hundred and sixty children between 3 and 18 years of age with developmental disabilities and their parents (child's $M_{\text{age}} = 8.10$, $SD = 3.75$) were enrolled from outpatient clinics at a pediatric medical center. Results revealed that children with adaptive care plans did not experience less psychosocial distress, and parents as well as medical staff did not perceive adaptive care plans to improve the effectiveness of healthcare encounters. Future research is needed to understand if adaptive care plans reduce psychosocial distress during and after medical procedures, and if children who have specific types of developmental disabilities experience benefit from these plans.

Keywords: adaptive care plan, patient-centered care, developmental disability, child life specialist

Effectiveness of Adaptive Care Plans for Children with Developmental Disabilities During Outpatient Clinic Appointments

Children with developmental disabilities experience significant challenges in the healthcare environment (Johnson & Rodriguez, 2013; Scarpinato et al., 2010). The challenges experienced by children with developmental disabilities are likely due, at least in part, to the difficult time they have cooperating with medical procedures (Johnson & Rodriguez, 2013). Because children with developmental disabilities have a higher number of medical diagnoses and, consequently, require more medical experiences than typically developing children (Levy et al., 2010; Schieve et al., 2012), it is important to examine interventions that may improve the healthcare experiences of children with developmental disabilities. The current study examines the effectiveness of adaptive care plans, which are personalized patient-centered treatment plans, to positively effect the healthcare experiences of children with developmental disabilities.

Developmental Disabilities and Prevalence

Developmental disabilities are recognized as “Chronic...conditions that typically originate during childhood; are likely to continue indefinitely; and require additional coordinated services, support, or other assistance for an extended duration or during a lifetime” (Boulet, Boyle, & Schieve, 2009, p. 19). Additionally, developmental disabilities “Affect cognition, behavior, and multiple body systems” (Zablitzky, Black, Maenner, Schieve, & Blumberg, 2015, p. 1) and include disorders such as attention deficit hyperactivity disorder (ADHD), moderate to profound hearing loss, blindness, learning disorders, cerebral palsy, autism spectrum disorder (ASD), intellectual disabilities, seizures, and stuttering or stammering (Boyle et al., 2011).

Generally, the prevalence of developmental disabilities in the United States is believed to be increasing, despite challenges in accurately estimating the rate of different developmental disabilities (because diagnostic criteria for individual disorders change over time; Zablotsky et al., 2015). For example, between 1997 and 2008, the prevalence of developmental disabilities increased among non-institutionalized children in the United States from 12.84 to 15.04% (Boyle et al., 2011), with some of this change attributed to increases in the rates of ASD (Boyle et al., 2011; Zablotsky et al., 2015). Reports of the prevalence of specific developmental disabilities in the United States from 2006 to 2010 revealed that 7.9% of children's primary diagnosis was ADHD, 7.8% a learning disability, 4.3% a general developmental delay, .9% ASD, and .7% an intellectual disability (Schieve et al., 2012). Although these data provide a good estimate of the prevalence of individual developmental disorders, they do not include data for secondary diagnoses among children who have two (or more) developmental disabilities. For example, among children diagnosed with ASD between 1991 and 2010, 40% also had an intellectual disability, 3% also had Cerebral Palsy, 1% also had hearing loss, and 1% also had a visual impairment (Van Naarden Braun et al., 2015). Overall, in 2015, the Centers for Disease Control and Prevention reported that approximately one in six children are diagnosed with one or more than one developmental disability. The relatively high, and apparently growing, proportion of children affected by one or more than one developmental disability has implications for the services provided to these children, including services provided during healthcare encounters.

Although healthcare encounters can be difficult experiences for all children, such encounters are especially challenging, and unfortunately more frequent, for children with developmental disabilities. Data from the 2006 to 2010 National Health Interview Survey revealed that children, aged 3 to 17, with developmental delays (e.g., cerebral palsy, deafness,

seizures, stuttering) were more likely than their typically developing counterparts to experience healthcare encounters (Schieve et al., 2012). Such data are consistent with research reporting increased rates of outpatient and emergency department visits among children with ASD or ADHD (Chan, Zhan, & Homer, 2002; Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Liptak, Stuart, & Auinger, 2006). Further, children with developmental disabilities have been found to be “2 to 8 times as likely [than typically developing children] to have had more than 9 healthcare visits (14.9%), had a surgical or medical procedure (7.5%), and recently visited a medical specialist (23.9%), mental health professional (26.6%), therapist/allied health professional (19.6%), and/or emergency department (10.3%)” (Boulet et al., 2009, p. 19).

One explanation for the higher frequency of healthcare encounters experienced by children with developmental disabilities, compared to typically developing children, is that children with developmental disabilities have a greater number of medical diagnoses and, consequently, require more medical experiences than typically developing children (Levy et al., 2010; Schieve et al., 2012). For example, individuals with ASD commonly have co-occurring seizure disorders, sleep difficulties, gastrointestinal problems, and learning and psychological difficulties (Bellando & Lopez, 2009; Leyfer et al., 2006; Manning-Courtney et al., 2003; Myers, Johnson, & The Council on Children with Disabilities, 2007). Further, in comparison to typically developing children, children with developmental disabilities experience moderate to marked increases in asthma and recurrent ear infections, respiratory, skin, and dietary allergies, severe headaches, diarrhea, seizures, and stuttering (Schieve et al., 2012). Unfortunately, the greater number of medical diagnoses and, therefore, the greater number of healthcare encounters experienced by children with developmental disabilities does not result in higher quality of care.

Challenges in Healthcare Encounters for Children with Developmental Disabilities

Children with developmental disabilities experience many challenges in the healthcare environment (Bultas et al., 2016). The challenges experienced by children with developmental disabilities occur, in part, because they tend to engage in relatively high rates of problem behaviors (Kogan et al., 2008). The problem behaviors that children with developmental disabilities tend to display during healthcare encounters can contribute to their unmet healthcare needs and the poor quality of healthcare services received.

Despite experiencing more healthcare appointments than typical developing children, children with developmental disabilities also have a higher percentage of unmet healthcare needs. Through a national survey of over 39,000 parents of children with developmental disabilities, over 23% of children were found to have more than one unmet healthcare need in the past 12 months (Centers for Disease Control and Prevention's National Center for Health Statistics, 2010). Additionally, Liptak et al. (2006) found that parents of children with ASD rated their PCP lower than parents of children with other developmental disabilities on the PCP's ability to answer questions about the child's ASD. These parents also reported less confidence in the PCP's ability to manage the child's medical conditions. Consistent with these results, Kogan et al. (2008) found that parents of children with ASD were more likely to have unmet healthcare needs for specific healthcare services, have unmet family support concerns, and be more likely to have delayed or forgone care compared to parents of children who have other special healthcare needs.

Russell and McCloskey (2016) completed a qualitative study that examined the healthcare perceptions of parents of children with ASD. Among the themes that emerged, parents acknowledged the lack of support that the child's PCP provided during the healthcare visit, reported that their child's PCP was not knowledgeable about their child's developmental

diagnosis (ASD), and the PCP was not able to provide social support and community resources. Consequently, these parents reported only taking their child to PCP appointments for serious acute medical conditions or when annual physicals were absolutely necessary. For children who will likely require lifelong mental and/or physical healthcare services, having a supportive partnership with a PCP is crucial to receiving optimal healthcare services.

Concerned about the challenges that children with developmental disabilities experience during healthcare encounters, and motivated to better understand the barriers preventing quality medical care to children with ASD, Bultas et al. (2016) surveyed parents of children with ASD and healthcare providers (physicians and nurse practitioners). Furthermore, Bultas et al. revealed that parents (42%) most commonly reported that the healthcare provider did not fully understand how ASD impacted the life of the child and the child's medical care. Parents (24%) also described environmental barriers to healthcare visits for children with ASD that included long waits, bright lights, and crowded waiting areas. Lastly, parents' responses (24%) revealed that the child's ASD-related challenging behaviors were a barrier to receiving quality medical care. In contrast to the parents' responses, the healthcare providers' survey responses revealed that the large majority of healthcare providers (78%) attribute the child's uncooperative behavior as the largest barrier to productive healthcare visits. Healthcare providers also acknowledged the influence of the child's fears (67%), communication barriers (55%), and parents' feelings of being overwhelmed with the healthcare experience (53%) as barriers to productive healthcare encounters. Although parents and healthcare providers appear to have some disagreements on the major barriers to quality care for children with developmental disabilities, both agree that the challenging behavior demonstrated by children with developmental disabilities inhibits productive healthcare visits.

Problem or challenging behaviors are an obstacle to receiving quality care during healthcare encounters for many children with developmental disabilities. For example, among children at risk for displaying problem behaviors during healthcare encounters (e.g., children with ADHD, ASD, behavioral or conduct problems), over 23% had one or more than one unmet healthcare need across a 12-month period (Centers for Disease Control and Prevention's National Center for Health Statistics, 2010). Further, Kogan et al. (2008) found that children with autism who have emotional or behavioral problems were more likely to have unmet healthcare needs, experienced delayed or foregone care, or received ineffective care compared to children without autism who had special healthcare needs. The impact of problem behaviors displayed by children with developmental disabilities during healthcare encounters is so apparent that both parents and healthcare providers recognize that the children's uncooperative behavior is a barrier to productive healthcare visits (Bultas et al., 2016).

Problem behaviors.

Problem or challenging behaviors are thought to occur in approximately 10 to 60 percent of individuals with developmental disabilities (Emerson, Moss, & Kiernan, 1999) and include behaviors such as non-compliance, hyperactivity, sensory challenges, and self-injurious behaviors (Johnson & Rodriguez, 2013). In a healthcare setting, when children's behaviors reach an intensity, frequency, or duration that prevent normal functioning or serve as a threat to the health and safety of themselves or those around them (e.g., parents, nursing staff, physicians), the behaviors are considered problematic (Dosen & De Groef, 2015).

The problem behaviors typically associated with developmental disabilities complicate the delivery of healthcare services for children with developmental disabilities because the problem behaviors are often exacerbated in a healthcare environment. Specifically, children with

developmental disabilities may be unprepared or unwilling to deal with the demands or expectations of healthcare providers in an acute care setting leading to poor compliance or non-compliance during the healthcare encounter (Loo, Graham, & Hughes, 2009). Additionally, environmental factors, such as not having appropriate toys or materials to direct their attention, leave children with developmental disabilities under-stimulated and feeling bored (Bultas, 2012). When examining the poor healthcare compliance of children with developmental disabilities, a significantly higher proportion of children with ASD exhibit uncooperative behaviors during an acute healthcare visit compared to children without ASD (Loo et al., 2009). The heightened uncooperative behaviors among children with ASD are consistent with prior research demonstrating that children with ASD have difficulty regulating their emotions and communicating their fears which, in turn, can lead to externalizing behaviors such as scratching, head butting, hitting others, and engaging in the destruction of property in the healthcare environment (Bultas, 2012; Gurney, McPheeters, & Davis, 2006; Scarpinato et al., 2010).

Contributing to these difficulties, physicians, nurses, and allied health professionals all report having little confidence in managing the challenging behaviors of children with developmental disabilities during healthcare appointments (Ong et al., 2017), leading to less than optimal healthcare experiences. Further, the lack of confidence among healthcare providers to manage the challenging behaviors of children with developmental disabilities is recognized by parents. Specifically, parents have identified the healthcare provider's lack of confidence, knowledge, and skills as reasons for the poor healthcare experiences (Liptak et al., 2006; Minnes & Steiner, 2009). Therefore, it is clear that the challenging behaviors displayed by children with developmental disabilities contribute to their less than optimal healthcare experiences.

Interventions for Healthcare Encounters

Researchers have offered several recommendations or strategies that healthcare providers may use to improve the healthcare experiences of children with developmental disabilities. Strategies or interventions have primarily focused on addressing the immediate needs of children *during* the healthcare experience, as well as strategies that healthcare providers can implement *prior to* the healthcare appointment. Among the interventions that primary focus on assisting children during healthcare experiences are positive reinforcement and distraction. Parents of children with a developmental disability and healthcare providers agree that using developmentally appropriate positive reinforcement (e.g., praise and reward) during healthcare encounters effectively reduces children's anxiety while simultaneously acknowledging the children's accomplishments, which can include compliant behavior (Johnson, Bekhet, Robinson, & Rodriguez, 2014). In addition to the use of reward as a form of positive reinforcement, distraction techniques have also been found to be beneficial for improving children's experiences with medical procedures. Mothers and healthcare providers both report that using distraction via play during healthcare appointments (e.g., iPads, sensory manipulatives) assists with reducing problem behaviors exhibited during long appointment wait times and invasive medical procedures (Johnson et al., 2014). Other common distraction techniques involve using conversation, singing, counting, and playing with toys (Souders, Freeman, DePaul, & Levy, 2002).

Along with interventions used during healthcare encounters, such as positive reinforcement and distraction, interventions developed *prior to* healthcare experiences can assist children with developmental disabilities reduce the distress associated with their healthcare experience. These interventions include picture or visual schedules, coping kits, and Quick Tip Cards. Visual or picture schedules depict the steps of an activity or experience and help children

understand what is expected of them during non-routine situations (Chebuhar, McCarthy, Bosch, & Baker, 2013), and these schedules tend to benefit children who struggle with understanding and processing verbal communication (Johnson et al., 2014). Therefore, step-by-step visual images help to prepare the children for medical experiences. Another effective strategy designed to support the needs of children with developmental disabilities is the use of “coping kits”, which require healthcare staff to prepare and provide simplistic communication cards, preparation books about the medical center, thera-tubing (to chew or play with), a stress ball, and a light spinner toy (Drake, Johnson, Stoneck, Martinez & Massey, 2012). In addition to visual schedules and coping kits, Quick Tip Cards are an effective tool for providing information about a child’s unique challenges in primary care settings to medical staff who may be less familiar with the child’s specific needs (Bulaas et al., 2016). Parents are asked to keep a notepad of the cards and complete the Quick Tip Card topics and sentence starters on their child’s unique challenges or characteristics (e.g., preferred style of communication, sensory concerns, problematic behaviors, calming strategies, fears related to the visit, and immediate mood) prior to their child’s healthcare encounters. Although not documented in the child’s electronic medical record, the information acquired from the Quick Tip Cards aids the productivity of the healthcare visit by providing medical staff information about the child that may complicate the healthcare visit.

Regardless of the specific intervention used to improve the healthcare experiences of children with developmental disabilities, effective healthcare encounters tend to be family or patient centered (Committee on Hospital Care and Institute for Patient- and Family-Centered Care, 2012). Family-centered care (Espe-Sherwindt, 2008), which is a form of patient-centered care that occurs in a pediatric setting, describes optimal healthcare for children with developmental disabilities as experienced by the families. Family-centered care views families

as partners or collaborators in the process of healthcare delivery to children, by providing caregivers with some control in the medical decision-making process (Dunst, Trivette, & Deal, 1994). Family-centered care is founded on six principles (information sharing, respect and honoring differences, partnership and collaboration, negotiation, and care in the context of family and community) aimed at promoting effective healthcare experiences for children with developmental disabilities (Kuo et al., 2012). In a study examining parents' perceptions of family-centered care practices for children with neurodevelopmental disabilities (including children with ASD and ADHD), Zajicek-Farber, Lotrecchiano, Long, and Farber (2015) revealed that 46% of parents viewed the ability to partner with a healthcare provider to make healthcare decisions for their child as a strength of family-centered care. Parents also viewed the ability to resolve disagreements in healthcare decisions (66%) and consideration of the child's ability to tolerate medical procedures (82%) as strengths of family-centered care. Further, family-centered care principles can assist in improving parents' satisfaction with the care provided to children with developmental disabilities.

Adaptive Care Plans

A relatively new and promising intervention for improving the healthcare experiences of children with developmental disabilities are adaptive care plans, which are individualized, patient-centered treatment plans intended to promote positive healthcare experiences for children with developmental disabilities. Adaptive care plans are created through collaboration between caregivers of children with developmental disabilities and medical staff in an attempt to anticipate the psychosocial challenges that may be experienced by children with developmental disabilities in a healthcare setting (Liddle, Birkett, Bonjour, & Risma, 2018).

Adaptive care plans were created in 2009 at Cincinnati Children's Hospital Medical Center (CCHMC) in response to children with developmental disabilities missing healthcare appointments or attending appointments that were non-productive in nature (Liddle et al., 2018). Unfortunately, there is a paucity of research on the use and effectiveness of adaptive care plans. Currently, only three studies have examined the effectiveness of adaptive care plans for improving the healthcare experiences of children with ASD, behavioral, and/or special needs (see Balakas, Gallaher, & Tilley, 2015; Broder-Fingert et al., 2016; Wittling, Dufur, McClain, & Gettis, 2018). In one study by Balakas et al. (2015), prior to the perioperative appointment, nurses assessed children's previous experiences in healthcare settings, reactions to new and stressful situations, communication strategies, sensory sensitivities, coping abilities, behavioral medications, and pain responses. Then, the nurses developed adaptive care plans that identified specific strategies or adaptations that may be effective in reducing the children's behavioral challenges. These strategies included changing the environment, decreased wait time prior to surgery, augmented communication among perioperative staff to improve the continuity of care, deferred vital signs if a child had sensory sensitivity to touch or pressure, and use of a "quiet zone" sign on exam room doors. After the children's experience in the postoperative area, parents rated their perceptions of the healthcare experience ($n = 68$). A majority of parents reported being satisfied (18.5%) or highly satisfied (48.5%) with the quality of care offered using the adaptive care plans.

Wittling et al. (2018) was interested in understanding how adaptive care plans influence healthcare personnel's level of comfort and knowledge of interventions specific to children with developmental disabilities, as well as how adaptive care plans influence healthcare staff's timeliness. In Wittling et al.'s study, child life specialists, members of the multidisciplinary

healthcare team who work to reduce a child and family's stress associated with the medical experience (American Academy of Pediatrics, 2014), collaborated with parents of children with ASD to create adaptive care plans (called "coping plans", p. 135). These plans were developed prior to surgical experiences and designed to reduce anxiety for both children with ASD and their caregivers. The child life specialists addressed the child's fears and stressors, calming strategies, motivators, and preferences surrounding medication and then collaborated with the medical team to provide accommodations, which included placing a sign on the patient's door, providing registration in the patient's room, and consulting with the anesthesiologist on alternative methods of sedation or anesthesia. Additionally, this information was integrated into the child's electronic medical record. After the implementation of adaptive care plans, 87% of the healthcare staff ($n = 57$) reported that their comfort level, time management abilities, and knowledge of interventions for children with ASD had increased compared to before the plans were implemented.

In the third known study examining the effectiveness of adaptive care plans to improve the healthcare experiences of children with developmental disabilities, Broder-Fingert et al. (2016) created adaptive care plans for children with ASD experiencing an inpatient admission. Broder-Fingert et al. asked physicians (and trainees) and parents of children with ASD to collaborate to develop adaptive care plans (called "autism-specific care plans", p. S196), which included assessing the topics of safety, communication, and social interactions of 2- to 21-year-old children with ASD. Information obtained from the physicians and parent collaboration was then documented in the children's electronic medical records for use during future inpatient admissions. One year later, a retrospective chart review ($n = 142$) revealed no differences in the number of documented safety reports between children with or without the adaptive care plans.

Parents of children with ASD who had adaptive care plans and parents of children with ASD who did not have adaptive care plans were sent a follow-up survey (n = 92; 65% response rate). Parents of children with the adaptive care plans reported better overall healthcare experiences, as well as increases in staff attention, compared to parents of children without adaptive care plans. Additionally, parents whose children had adaptive care plans reported that the medical staff listened carefully and helped their child deal with the stress and fear associated with the hospital experience more often than parents of children without adaptive care plans.

Based on the research by Balakas et al. (2015), Wittling et al. (2018), and Broder-Fingert et al. (2016), when adaptive care plans are utilized by medical personnel for the treatment of children with developmental disabilities, the care plans appear to increase parents' satisfaction with the healthcare experience, and healthcare staff appear to have increased comfort level working with children with developmental disabilities. Additionally, parents appear to find the plans to be effective in addressing their child's healthcare challenges.

Role of child life specialists in the delivery of adaptive care plans.

Child life specialists are healthcare professionals and members of a multi-disciplinary team that are well trained to work with typically and non-typically developing children. Child life specialists work in pediatric healthcare settings with the role of minimizing anxiety and stress while simultaneously promoting the coping of children and families during healthcare encounters (American Academy of Pediatrics, 2014). Child life specialists are the healthcare providers primarily responsible for the development and delivery of adaptive care plans (Liddle et al., 2018; Wittling et al., 2018).

According to the American Academy of Pediatrics' policy statement on child life services, the role of child life specialists includes addressing the psychosocial concerns of

infants, children, adolescents, and young adults that experience healthcare encounters or hospitalizations (2014). In order to help children and families cope with healthcare encounters, child life specialists use creative arts and developmentally appropriate play materials. The child life specialists provide education about medical diagnoses, preparation and support during medical procedures, rehearsal of coping strategies to address stress and pain, methods to process feelings regarding diagnoses and hospitalization, and encouragement of family involvement in the healthcare environment to promote positive developmental trajectories. Child life specialists frequently work in pediatric inpatient medical units, acute care units, rehabilitation units, emergency departments, and ambulatory or outpatient clinics.

It is common for child life specialists to work with children with chronic illnesses to improve coping and adaptation to healthcare encounters through the use of play, preparation, and developmentally appropriate communication (Hicks & Davitt, 2009). Both parents and medical staff recognize child life specialists as healthcare professionals that provide therapeutic distraction techniques and a calming presence for children with developmental disabilities and their caregivers during procedures and long wait times (Balakas et al., 2015; Johnson et al., 2014). Additionally, Taghon, Bryan, and Kurth (2006) recommend that a child life specialist become involved in the healthcare experience of children with developmental disabilities undergoing MRI, CT, or Nuclear Medicine procedures to assist in decreasing the child's anxiety as well as provide distraction during the procedures. Therefore, child life specialists are well prepared and trained in assisting children, including those with developmental disabilities, to cope with hospital experiences.

Current Study

Because children with developmental disabilities have more medical conditions than typically developing children, and therefore, experience more healthcare appointments (Levy et al., 2010; Schieve et al., 2012), examining the effectiveness of adaptive care plans designed to promote positive healthcare experiences for children with developmental disabilities is particularly important. Further, examining parents or legal guardians' perceptions of the effectiveness of adaptive care plans to improve the healthcare experiences of children with developmental disabilities may determine if the caregiver and child return for future appointments. Research has revealed that missed healthcare appointments for children with ASD may lead to delays in treatment, potentially resulting in delayed cognitive, language, or social development (Kalb et al., 2012).

The purpose of the current study is to assess the effectiveness of adaptive care plans because many hospital systems are introducing the plans to patients and families, and there is little research supporting their use (Liddle et al., 2018). Specifically, the current research is the first study to evaluate the effectiveness of adaptive care plans using an objective measure of psychosocial distress as well as evaluate the perceived effectiveness of the healthcare experience by medical staff caring for children with developmental disabilities. Based on previous research, it is predicted that children with developmental disabilities who have adaptive care plans will demonstrate lower psychosocial distress (i.e., as assessed by scores on the Psychosocial Risk Assessment in Pediatrics [PRAP]; Staab, Klayman, & Lin, 2014) than children with developmental disabilities who do not have adaptive care plans. It is also hypothesized that the parents or legal guardians of children who have developmental disabilities and the medical staff caring for the children will perceive healthcare experiences as more effective when adaptive care plans are present rather than absent. Finally, it is predicted that the invasiveness of the procedure

will moderate the effect of the adaptive care plans on children's psychosocial distress (as assessed by PRAP scores), such that children with adaptive care plans will experience lower PRAP scores than children without adaptive care plans, and this will be especially true for invasive compared to non-invasive procedures.

Method

Participants

Children between 3 and 18 years of age (see Table 1 for demographic information) with documented developmental disabilities, and their parents or legal guardians, were recruited from outpatient clinics through Cincinnati Children's Hospital Medical Center (CCHMC). All child participants were accompanied by and had the consent of their parent or legal guardian (Appendix A).¹ To be eligible to participate in the study, children had a Psychosocial Risk Assessment in Pediatrics (PRAP) score or an anticipated PRAP score of 8 to 24 (see below for details regarding measurement of the PRAP). Children and their parents or legal guardians were excluded from the study if the parent or legal guardian was not 18 years of age or older and if the parent or legal guardian did not read or speak English. An a priori power analysis, for a two-group design, indicated that for a medium (Cohen's $d = .50$) effect size, with a power of 80% and .05 significance level, 70 children and their parents or legal guardians were needed in each group, for a total of 140 children and parent or legal guardians (Cohen, 1977; Cohen, 1992). In order to compensate for potential missing data, a total of 160 children and parent or legal guardians were recruited to participate.

¹ Research involves children with developmental disabilities who may not be able to, nor will be asked to, provide assent. Because children experience the medical procedure regardless of their involvement in the study, data from the child's medical experience were only included in the study if parents or legal guardians provide consent.

One-hundred and sixty children and their parents or legal guardians participated in the study (96%) with only six parents or legal guardians declining participation (child's $M_{\text{age}} = 8.10$, $SD = 3.75$; see Table 1). On average, children included in the study had two developmental disabilities ($M = 2.43$, $SD = .98$). As seen in Table 2, most children had autism spectrum disorder ($N = 59$), expressive-receptive language disorder ($N = 50$), global developmental delay/unspecified developmental delay ($N = 41$), and/or a general language or speech delay ($N = 36$).

Children were enrolled from 16 outpatient clinics at CCHMC (i.e., allergy, cancer and blood diseases, complex care, dermatology, developmental and behavioral pediatrics, endocrinology, ear, nose, and throat, gastroenterology, neurology, ophthalmology, orthopedics, pediatric rehabilitation, plastics, pulmonology, test referral center, and urology). The most common procedures experienced by children in these clinical areas included blood draws ($N = 49$), botulin or Botox injections ($N = 26$), physical exams ($N = 22$), eye exams ($N = 19$), discussion only visits ($N = 17$), and dilation or eye drops ($N = 16$; see Table 3). Only 35 children in the study experienced more than one procedure during their healthcare visit. The children's medical procedures were coded for invasiveness according to the National Cancer Institute's definition, where an invasive procedure "invades (enters) the body, usually by cutting or puncturing the skin or by inserting instruments into the body" (2019). Therefore, medical procedures were coded as either invasive or non-invasive, with non-invasive procedures including those in which a discussion is held with the child and parent or legal guardian and those in which vitals (i.e., height, weight, blood pressure, and temperature) were obtained (see Table 3 for the dichotomization of invasive and non-invasive medical procedures). Among all children participating in the study 88 (55%) experienced an invasive procedure.

CCHMC medical staff working with the child participants in the outpatient clinics were also recruited to participate in the study. Medical staff included physicians (i.e., residents and fellows), registered nurses, advanced practice registered nurses, medical assistants or patient care assistants, and ophthalmological technicians.² Most commonly, medical assistants or patient care attendants ($N = 57$) and registered nurses ($N = 52$) participated in the study (see Table 4).

Measures

Parent or legal guardian and medical staff survey. Two parallel, eight-question, surveys were developed for this study to measure parent's or legal guardian's and medical staff's perceived effectiveness of the healthcare visit (Appendix B and C, respectively). Questions on the survey assessed the parent's or legal guardian's and medical staff's perception of the purpose of the child life specialist ($n = 3$; items 3, 4, and 5), the value of the service provided by the child life specialist ($n = 2$; items 6 and 7), if the parents or legal guardians or medical staff members would recommend the service to others ($n = 2$; items 1 and 8), and the perceived value of the patient-centered nature of the adaptive care plans ($n = 1$, item 2). All questions were rated on a 7-point Likert scale ranging from 1 (*entirely disagree*) to 7 (*entirely agree*). After reverse scoring the one negatively keyed question, scores were averaged, with higher scores reflecting greater perceived effectiveness of the healthcare visit. Initial evidence for the survey's content validity was established by asking two clinically advanced child life specialists and the director of the child life division at CCHMC to evaluate the appropriateness of the items to assess the effectiveness of healthcare visits involving adaptive care plans (see Chao & Green, 2011 for similar procedures used to establish content validity in newly developed measures). Further, to

² When CCHMC's medical staff complete research materials as part of their job duties, informed consent is not required.

ensure ease of readability, an education consultant within the Center for Professional Excellence at CCHMC reviewed and provided feedback. There are currently no psychometric data on the parent or legal guardian or medical staff surveys.

Psychosocial Risk Assessment in Pediatrics (PRAP). The PRAP is a tool used by child life specialists to assess distress in children ages 3 to 18 during healthcare encounters (Staab et al., 2013; see Appendix D). The PRAP was used to assess children's healthcare experiences on each of the following eight areas: communication, special needs, temperament, anxiety and coping during the healthcare encounter, parent/caregiver stress, past healthcare encounters, invasiveness of procedure/encounter, and developmental impact (of the procedure). All certified child life specialists at CCHMC are trained on the use and documentation of the PRAP (K. Shamszad, personal communication, February 21, 2017). The child life specialist assessed a child after her or his healthcare encounter and assigned a score of 0 (indicating no challenges) to 3 (indicating severe challenges) for each of the eight areas assessed on the PRAP. The child life specialist then entered these scores into CCHMC's electronic medical record as well as a national de-identified online database (i.e., praptool.com). A total PRAP score was calculated by summing the eight sub-component scores. The PRAP is a highly used measure of children's psychosocial distress and has sound psychometric properties (see Staab et al., 2013).

Procedure

CCHMC and Xavier University IRB approval (see Appendix A) was obtained prior to conducting the proposed study. After gaining the IRB approvals, and prior to data collection, information sessions were held for certified child life specialists involved in the study to describe the purpose of the research as well as to provide an opportunity for questions. After the information sessions, the primary researcher used CCHMC's "electronic report generating

system” to identify participants for possible inclusion into the study. The primary researcher and trained child life specialists reviewed future outpatient clinic schedules through the electronic medical record to identify child participants for possible inclusion into the study based on the child’s PRAP or anticipated PRAP score. Children and their parent or legal guardians were selected for inclusion into one of two possible groups. The first group consisted of children with appointments to outpatient clinics located at CCHMC’s Burnet Avenue campus who had an *existing* individualized adaptive care plan as identified in CCHMC’s electronic medical record. The children in this group had an existing individualized adaptive care plan because they scored between 8 and 24 on the PRAP as assessed by a child life specialist. The second group (or comparison-control group) consisted of children with appointments to outpatient clinics who did not have an existing individualized adaptive care plan. Specifically, for inclusion in the comparison-control group, children must have a documented developmental disability, and have *anticipated* PRAP scores in the moderate (scores between 8 and 14) to high (scores between 15 and 24) range, as identified through a review of the children’s electronic medical record.

Identification of potential participants occurred prior to the children’s appointment. When a pre-identified child and his/her parent or legal guardian arrived to the child’s outpatient appointment and entered an exam room, a trained child life specialist greeted the child and parent or legal guardian and introduced her or himself and her or his role as a child life specialist. The child life specialist then informed the parent or legal guardian about the purpose of the current study and asked if she or he would like to participate with her or his child, respectively. If the parent or legal guardian agreed to participate, the child life specialist read aloud or allowed the parent or legal guardian to read the informed consent document. Parents or legal guardians that

consented signed one copy of the informed consent (giving it to the child life specialist) and received a second copy to keep.

During the outpatient procedure, a child life specialist supported each child participant and his/her parent or legal guardian. The child life specialist provided interventions aimed to decrease the child's distress and increase coping. For children in the experimental group, the interventions provided by the child life specialists were determined by the children's *existing* adaptive care plans and were individualized based on the children's specific needs (see Appendix E). For children in the comparison-control group, the interventions provided by the child life specialists were determined during the outpatient procedure based on the immediate needs of the child (Squires & Allen, 2009; Wolfer, Gaynard, Goldberger, Ludley, & Thompson, 1988).

When the medical visit was complete, the parent or legal guardian was asked to complete the parent or legal guardian survey, administered through CCHMC's electronic survey system called REDcap. Simultaneously, the child life specialist identified the primary medical staff, who spent the most time in the child's room, to complete the medical staff survey, which was also administered through the REDcap system. The child life specialist then documented in the electronic medical record per CCHMC's protocol (i.e., the child's PRAP score, PRAP ID number, and information about the appointment). The child life specialist also documented in the PRAP online database as usual).

It should be noted that, after completion of the study, parents/legal guardians of children in the comparison-control group were asked if they would like their child to be added to the referral list for the development of an adaptive care plan (because they meet criteria for an adaptive care plan with an anticipated PRAP score of 8 to 24). If the parent or legal guardian

wanted an adaptive care plan developed for his/her child, the child's identifying information was placed on a HIPPA compliant list for future contact by an adaptive care team child life specialist.

Results

Preliminary Analyses

Data screening. Tabachnik and Fidell's (2013) recommendations for data screening were followed prior to conducting the primary analyses in order to examine the data for violations to the assumptions of the general linear model. Data screening included performing analyses to identify outliers using z scores (with outliers identified as values exceeding ± 2.5), understand normality using the Shapiro-Wilks test, and determine homogeneity of variance using Levene's test. Twelve outliers were detected; z scores revealed one outlier from the total PRAP scores (in the adaptive care plan condition), four outliers from the parents or legal guardians survey, and seven outliers from the medical staff survey. Because outliers can impact the outcome of statistical analyses, each outlier was edited to reflect the next most extreme score within the normal distribution of scores.

To determine if the shape of the distribution of scores for the continuous variables in the current study (by condition) was normal, results from Shapiro-Wilks test were examined. Results revealed that scores on the total PRAP measure for children without an adaptive care plan ($.97, p = .004$, the parents or legal guardians survey ($.49, p = .001$), and the medical staff survey ($.34, p = .001$) departed from normality. Because the General Linear Model is robust to violations of its assumption of normality, no transformations of the data were made. Finally, Levene's test assessed the homogeneity of variance for scores on the total PRAP, the parent or legal guardian survey, and the medical staff survey for children with and without adaptive care plans. Results revealed homogeneity of variance for the study's criterion variables; variability in scores for the total PRAP ($3.36, p = .07$), the parent or legal guardian survey ($<.001, p = 1.0$), and the medical staff survey ($3.36, p = .07$) were similar for children with and without adaptive care plans. Means

and standard deviations associated with all criterion variables in the study are reported in Table 5.

Covariate. To examine if chronological age of a child is associated with total PRAP and PRAP subscale scores (assessed after the medical procedure) for children with and without adaptive care plans, bivariate correlations were computed (see Table 7). Results revealed that the child's age was not correlated with total PRAP scores, but was positively correlated with scores on four of the eight PRAP subscales, specifically the special needs (i.e., mental, physical, developmental, behavioral, and psychological challenges that affect healthcare experience), temperament (i.e., adaptability to healthcare experiences), invasiveness (i.e., invasiveness of the procedure or appointment as perceived by the child life specialist on behalf of the child), and the developmental impact (i.e., the child's developmental level that impacts his or her ability to cope with the healthcare encounter) subscales. Thus, for any analysis involving PRAP subscale scores described below, chronological age of a child was entered as a covariate.

Primary Analyses

To test the prediction that adaptive care plans for children with developmental disabilities positively affect their psychosocial outcomes compared to children with developmental disabilities who do not have adaptive care plans, a one-way between-groups MANCOVA was conducted with age as the covariate and PRAP subscale scores as dependent variables. Results revealed a significant multivariate effect for adaptive care plan, Pillai's trace = .22, $F(8, 150) = 5.135$, $p < .001$. Follow-up ANCOVAs (see Table 7) for each of the PRAP subscales (i.e., communication, special needs, anxiety and coping, temperament, parent stress, past healthcare encounter, invasiveness, and developmental impact), using a Bonferonni corrected value of $p < .006$, revealed univariate effects of adaptive care plan on the PRAP special needs, $F(1, 157) =$

14.66, $p < .001$, temperament, $F(1, 157) = 21.98$, $p < .001$, and past healthcare encounter, $F(1, 157) = 8.60$, $p = .004$, subscales. Children with developmental disabilities who had adaptive care plans had a greater number of mental, physical, developmental, behavioral, and psychological challenges (i.e., special needs), were less adaptable (i.e., temperament), and had a higher number of difficult past healthcare encounters that were impacting coping (i.e., healthcare encounters) compared to children with developmental disabilities who did not have adaptive care plans.

A one-way between-groups ANOVA was conducted with the total PRAP scores as the dependent variable to evaluate if adaptive care plans for children with developmental disabilities have a positive effect on psychosocial outcomes compared to children with developmental disabilities who do not have adaptive care plans. Results revealed higher total PRAP or psychosocial distress scores, $F(1, 158) = 3.90$, $p = .05$, for children with developmental disabilities who had adaptive care plans ($M = 10.34$, $SD = 2.73$) compared to children who did not have adaptive care plans ($M = 9.55$, $SD = 2.29$).

To examine if parents or legal guardians of children with developmental disabilities perceive that adaptive care plans positively affect the healthcare experiences compared to parents or legal guardians of children who do not have adaptive care plans (pre-identified as moderate to high distress on the PRAP), an independent-samples t -test was conducted (using a significance level of $p < .05$). Results revealed no significant difference in parents or legal guardians' perceptions of the effectiveness of the healthcare experience for children who had ($M = 6.67$, $SD = .61$) or did not have ($M = 6.59$, $SD = .58$) adaptive care plans, $t(158) = -0.85$, $p = .40$.

To examine if medical staff perceive that adaptive care plans have a greater effect on effective healthcare experiences for children with developmental disabilities who had or did not have adaptive care plans (pre-identified as moderate to high distress on the PRAP), an

independent-samples *t*-test was conducted (using a significance level of $p < .05$). Results revealed no significant difference in medical staffs' perceptions of the effectiveness of healthcare experiences for children with developmental disabilities who had ($M = 6.81$, $SD = .31$) or did not have ($M = 6.82$, $SD = .29$) adaptive care plans, $t(157) = 0.15$, $p = .88$.

A 2 x 2 between-groups factorial MANCOVA, controlling for age, was conducted to examine if the invasiveness of a medical procedure (see Table 3 for the operationalization of invasive and non-invasive medical procedures) experienced by children with or without an adaptive care plan affects PRAP subscale scores. Results revealed a multivariate main effect of invasiveness, Pillai's Trace = .30, $F(8, 148) = 7.83$, $p = .001$, but no multivariate effects for adaptive care plan, Pillai's Trace = .12, $F(8, 148) = 2.40$, $p = .20$, or the interaction between adaptive care plan and invasiveness, Pillai's Trace = .04, $F(8, 148) = .75$, $p = .64$. To examine the multivariate main effect of invasiveness, follow-up one-way ANCOVAs (see Table 8) were conducted for each of the PRAP subscales (i.e., communication, special needs, anxiety and coping, temperament, parent stress, past healthcare encounter, invasiveness, and developmental impact), using a Bonferonni corrected value of $p < .006$. Results revealed a significant difference for invasiveness on the PRAP subscale of anxiety and coping (i.e., anxiety that can impair coping; $F(1, 155) = 10.11$, $p = .002$), with children experiencing more invasive procedures ($M = 1.47$, $SD = .84$) having higher levels of anxiety and lower levels of coping than children who experienced less invasive procedures ($M = 1.17$, $SD = .61$). Results also revealed a significant difference for invasiveness of the medical procedure on the PRAP subscale of invasiveness, which reflects the child life specialist's perceptions of how invasive the child's perceives the healthcare experience, $F(1, 155) = 33.28$, $p < .001$. Children who experienced more invasive

healthcare procedures ($M = 1.87$, $SD = .80$) were perceived to experience the procedures as more invasive than children who experienced less procedures ($M = 1.10$, $SD = .74$).

Finally, to examine if invasiveness of a medical procedure experienced by a child with or without an adaptive care plan affects total PRAP scores (assessed after the medical procedure), a 2 x 2 between-groups factorial ANOVA was conducted. Results revealed a main effect for adaptive care plan, $F(1, 156) = 6.19$, $p = .01$, but no effects for invasiveness, $F(1, 156) = 2.73$, $p = .10$, or the interaction between the adaptive care plan and invasiveness, $F(1, 156) = .11$, $p = .75$. Children with adaptive care plans ($M = 10.34$, $SD = 2.73$) had higher total PRAP scores – or levels of psychosocial distress – than children who did not have adaptive care plans ($M = 9.55$, $SD = 2.29$).

Discussion

Little research has examined the effectiveness of adaptive care plans as an intervention to decrease psychosocial distress for children with developmental disabilities during healthcare encounters. The current study examined if adaptive care plans positively affect the psychosocial outcomes among children with developmental disabilities, and greater parent or legal guardian and medical staff satisfaction with the healthcare visit, compared to children with developmental disabilities who did not have adaptive care plans. Contrary to expectations, compared to children with developmental disabilities who did not have adaptive care plans, children with adaptive care plans were perceived to a) have higher total psychosocial distress, b) a greater number of mental, physical, developmental, behavioral, and psychological challenges, c) be less adaptable, and d) have a higher number of difficult past healthcare encounters that were impacting their coping. Further, regardless of whether the children had or did not have an adaptive care plan, when the children experienced more invasive procedures, they were perceived to have higher levels of

anxiety and lower levels of coping than children who experienced less invasive procedures. Additionally, parents or legal guardians of children with developmental disabilities and the medical staff caring for children with developmental disabilities did not perceive any differences in the effectiveness of the health care encounter for children with or without adaptive care plans. The present findings suggest that adaptive care plans do not seem to have a more positive effect on psychosocial outcomes and are not perceived as effective by parents or legal guardians and healthcare personnel.

One of the primary purposes of the study was to test the prediction that adaptive care plans for children with developmental disabilities positively affects the psychosocial outcomes during a healthcare experience compared to children with developmental disabilities who do not have adaptive care plans. Counter to expectations, when differences in psychosocial outcomes were observed, children with developmental disabilities who had adaptive care plans were found to have *greater* difficulties than children with developmental disabilities who did not have adaptive care plans. These findings suggest that having an adaptive care plan does not necessarily help children with developmental disabilities overcome the challenges experienced during outpatient appointments. One possible explanation for these findings is that psychosocial distress may not have been equivalent for children with and without adaptive care plans at the beginning of the study. Because the psychosocial distress score associated with children who did not have an adaptive care plan was estimated from a review of their electronic medical records, it is possible that these children's psychosocial distress was lower than children with existing adaptive care plans at the beginning of the study. Unfortunately, the problem of non-equivalent groups when examining the effectiveness of adaptive care plans is not isolated to the current study. For example, Broder-Fingert et al. (2016) conducted a retrospective chart review to

examine, among other variables, if children with adaptive care plans experience shorter hospital stays and fewer safety-related incidents compared to children without adaptive care plans.

Broder-Fingert et al. revealed no differences in the length of a hospital stay or number of safety-related incidents between children with and without adaptive care plans, possibly because children with more severe developmental disabilities were more likely (than children with less severe developmental disabilities) to have an adaptive care plan. The non-equivalence of groups in Broder-Fingert et al.'s research could explain their null results. Although challenging to overcome, future research should randomly assign children with developmental disabilities who will be experiencing healthcare encounters (without an already established adaptive care plan) to adaptive care plan or no adaptive care plan conditions. Such a procedure would ensure equivalence of the groups before assessing if the adaptive care plans can effectively reduce children's psychosocial distress during healthcare experiences.

Contrary to expectations, both the parents or legal guardians of children with developmental disabilities and the medical staff caring for children with developmental disabilities did not perceive adaptive care plans to positively affect healthcare encounters. Regardless of the presence or absence of an adaptive care plan, both parents or legal guardians and medical providers appeared to value the services provided by child life specialists, who they likely believed were influential in helping the child cope with the medical experience. Previous research by Gursky, Kestler, and Lewis (2010) and Madhok, Milner, Teele and Finkelstein (2007) has demonstrated that parents report greater satisfaction with their child's healthcare experience when a child life specialist provided interventions that attempted to reduce their child's fear and anxiety. Because child life specialists provided services to all children in the current study, parents may have perceived the healthcare experience as relatively effective

regardless of whether their child had an adaptive care plan or not. It is also possible that the medical staff caring for children with developmental disabilities in the current study recognized that child life specialists attempt to promote psychosocial wellbeing during medical encounters, whether or not adaptive care plans were present. Such an explanation has merit because Cole, Diener, Wright, and Gaynard (2001) revealed that among healthcare employees (i.e., physicians, nurses, social workers, and administrators) at one medical center, child life specialists were perceived as the most highly rated professional to positively influence children's psychosocial wellbeing during medical experiences. Additionally, according to the AAP (2014), child life specialists are healthcare professionals that are integral to providing high quality patient- and family-centered care. Because medical staff appear to appreciate child life specialists' role as providers of patient- and family-centered care, the medical staff in the current study may not have perceived differences in the effectiveness of healthcare encounters for children with or without adaptive care plans. Future research could examine the perceived effectiveness of healthcare encounters for children with developmental disabilities when child life specialists are and are *not* present during the encounter.

Further, the non-significant difference in the perceived effectiveness of healthcare encounters for children with or without adaptive care plans may be due to the lack of specificity in the measure of perceived effectiveness. The current study operationalized perceived effectiveness as an *overall* evaluation of the healthcare encounter that reflected the purpose of the child life specialist, the value of the services provided, if the services would be recommended to others, and if the services were patient-centered. Such a broad operationalization does not permit a direct and precise measure of what makes adaptive care plans effective (e.g., adaptations to hospital protocols that target individualization of communication strategies,

decreasing stressors and reducing challenging behaviors, addressing sensory needs, and recognizing unique pain presentations). In research that has demonstrated the effectiveness of adaptive care plans, Broder-Fingert et al. (2016) surveyed parents about *specific* interpersonal behaviors performed by medical staff (e.g., their attentiveness and ability to listen) as well as the staff's ability to help their child overcome fear associated with the hospital environment. Such specific behaviors are central to the work of child life specialists who implement adaptive care plans and, therefore, future research should develop a measure that precisely operationalizes effective adaptive care plans.

Regardless of the presence or absence of an adaptive care plan, children who experienced more invasive medical procedures were perceived (by child life specialists) to experience the procedure as more invasive and to respond with more anxiety and lower levels of coping than children who experienced less invasive medical procedures. However, there was no effect of invasiveness of the medical procedure on the overall psychosocial distress for children with developmental disabilities who had or did not have adaptive care plans. It is not surprising that invasive medical procedures cause higher levels of anxiety and contribute to decreased coping abilities compared to less invasive medical procedures. In a seminal study by Saylor et al. (1986), hospitalized children who had more physically stressful procedures were found to experience greater depression and anxiety symptoms as well as more behavioral upset (i.e., exhibit irritability, impatience, and become uncooperative) during their hospitalization compared to children experiencing less physically stressful procedures. In more recent research, Muranjan, Birajdar, Shah, Sundaraman, and Tullu (2010) and Rennick et al. (2004) revealed that children exposed to more invasive procedures reported experiencing a greater number of intrusive symptoms (i.e., nightmares, intrusive thoughts), a higher number of medical fears, and more

posttraumatic stress symptoms upon discharge from a pediatric intensive care unit than children exposed to less invasive procedures. Given the negative effects that invasive medical procedures have on children's wellbeing, future research could examine under what conditions, or what types of procedures, adaptive care plans help reduce children's psychosocial distress. Such research may find that the type of child life intervention, such as medical play or procedural preparation/support, may effectively reduce anxiety and distress for children with developmental disabilities undergoing specific types of medical experiences (see Brewer, Gleditsch, Syblik, Tietjens, & Vacik, 2006; Li, Chung, Ho, & Kwok, 2016; Moore, Bennett, Dietrich, & Wells, 2015).

Limitations and Future Directions

The present findings contribute to the body of literature on the use of adaptive care plans for children with developmental disabilities who have difficulties coping with medical encounters. Despite the valuable nature of the current study, there are limitations that may help to inform the direction of future research.

One limitation in the current study is that the type and frequency of developmental disorders were not equal between children who had or did not have adaptive care plans. For example, there were fewer children with an adaptive care plan diagnosed with cerebral palsy or global developmental delay, and a greater number of children with an adaptive care plan who had ASD, hearing loss, and language or speech delays (see Table 2). Although challenging behaviors occur for many children with developmental disabilities (Emerson et al., 1999), a significantly higher proportion of children with ASD exhibit uncooperative behaviors (e.g., scratching, head butting, hitting others, and engaging in the destruction of property in the healthcare environment) during acute healthcare visits compared to children without ASD

(Bultas, 2012; Gurney et al., 2006; Loo et al., 2009; Scarpinato et al., 2010). Because of the higher proportion of children with ASD in the adaptive care plan condition, it is unlikely that children with adaptive care plans would demonstrate *lower* distress compared to children without adaptive care plans. Although it is possible that the adaptive care plans may have *reduced* psychosocial distress among children with ASD, the between-groups nature of the current study's design does not allow for examining the *change* in distress among children with and without adaptive care plans. Therefore, future research could examine the change in psychosocial distress among children with and without adaptive care plans by assessing the children's distress during and after the medical procedures. Such research may find little change in distress among children without adaptive care plans, whereas decreases in distress may be observed for children with adaptive care plans.

Furthermore, given the variability in the type and frequency of developmental disorders experienced by children in the current study, future research could investigate if adaptive care plans are particularly effective for children with specific developmental diagnoses. Although Broder-Fingert et al. (2016) and Wittling et al. (2018) analyzed outcomes of adaptive care plans with children who had ASD, no research has investigated the effectiveness of adaptive care plans for any of the other prevalent developmental diagnoses. Further, in only one study (see Balakas et al., 2015) have researchers assessed the effectiveness of adaptive care plans for children with a variety of developmental disabilities (e.g., ASD, down syndrome, sensory processing), yet the authors did not publish the discrete numbers of children who had these developmental disabilities. Commonly, comorbid or co-occurring diagnoses appear among children with developmental disorders (Bax & Gillberg, 2010) and because many children tend to have more than one developmental diagnosis (e.g., children with ASD also tend to have expressive and/or

receptive language disorder and sensory integration disorder; see Lane, Young, Baker & Angle, 2010; Özyurt & Eliküçük, 2018), it may be methodologically challenging to determine if adaptive care plans are effective for isolated developmental disorders. Consequently, future research on adaptive care plans may benefit from examining children's primary diagnosis or cluster of diagnoses.

Finally, in the current study, nine child life specialists with varying levels of knowledge and experience with children who have developmental disabilities as well as varying levels of comfort implementing adaptive care plans participated. Four of these child life specialists typically provide care to children with developmental disabilities or children (and their families) who had existing adaptive care plans. The other five child life specialists usually provided child life support to children that were typically developing, and for the purposes of this study, received re-education on adaptive care plans when beginning their role within the research team. Consequently, because of the child life specialists' differing levels of experience with adaptive care plans, their fidelity to the plans is unknown. Specifically, the varying levels of staff knowledge and experience with implementing adaptive care plans may have led to inconsistencies implementing the plans and therefore affected the results. According to Garzonis, Mann, Wyrzykowska, and Kanellakis (2015), patient psychological outcomes are likely a consequence (at least in part) of mental health practitioner skill training. Consequently, it may be beneficial for future research to assess child life specialists' levels of experience and comfort, as well as barriers to implementing adaptive care plans. Although the child life specialists in the current study with less experience appeared to have little difficulty implementing adaptive care plans in outpatient clinics, future studies should explore the feasibility of adaptive care plans, such as the acceptability of adaptive care plans by child life specialists, the amount of resources

and time required to implement adaptive care plans, and the extent to which adaptive care plans are being implemented within a hospital setting (Bowen et al., 2009).

Additionally, Garzonis et al. (2015) suggest that mental health practitioners demonstrate increases in their level of competency when educational opportunities consider and plan for not only the skill to be obtained, but also desired patient outcomes. Based on Garzonis and colleagues' recommendations, using a collaborative, multidisciplinary group training may be an effective format to help child life specialists develop the skills necessary to properly implement adaptive care plans, which would include increasing their developmentally appropriate communication skills and spontaneously addressing children's mental and behavioral health challenges. Future research could also evaluate the format and content of the education and training that child life specialists receive about adaptive care plans to help ensure competency and consistency among specialists.

Conclusion

Although future research is needed to understand if children with developmental disabilities benefit from adaptive care plans, the current study suggests that children with adaptive care plans may not be experiencing a reduction in psychosocial distress compared to children without adaptive care plans. Additionally, for children with adaptive care plans, parents or legal guardians as well as medical staff do not appear to perceive adaptive care plans as improving the effectiveness of the healthcare encounter for children with developmental disabilities.

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Table 1

Number and Percentage of Participants by Race/Ethnicity and Age

Demographic Characteristic	<i>n</i>	%
Race/Ethnicity		
Asian	2	1.3
Black/African American	35	21.9
Bi-racial	2	1.3
Hispanic American/Latina	4	2.5
White/European American	117	73.0
Gender		
Female	56	35.0
Male	104	65.0
Age (in years)		
3	16	10.0
4	19	11.9
5	15	9.4
6	18	11.3
7	11	6.9
8	10	6.3
9	13	8.1
10	14	8.8
11	5	3.1
12	16	10
13	9	5.6
14	6	3.8
15	4	2.5
16	2	1.3
17	1	0.6
18	1	0.6

Table 2

Frequency of Developmental Disability

	Overall	ACP	No ACP
Attention deficit hyperactivity disorder	28	15	13
Autism spectrum disorder	59	37	22
Cerebral palsy	24	8	16
Encephalopathy	2	2	0
Expressive-receptive language disorder	50	28	22
Genetic conditions/ disorders	10	5	5
Global developmental delay/ unspecified developmental delay	41	2	40
Hearing loss (unspecified, bilateral, sensorineural)	10	7	3
Intellectual disability/ cognitive impairment	15	9	6
Language or speech delay	36	23	13
Learning disability	2	0	2
Motor delay (fine and gross motor)/ poor coordination	12	3	9
Other chromosomal abnormalities	6	5	1
Spina bifida	4	0	4
Trisomy 21	13	4	9
Vision Impairment	11	4	7
Total	323	152	172

Note. ACP = Adaptive Care Plan; No ACP = No Adaptive Care Plan.

Table 3

Frequency of Each Medical Procedure and Categorization as Invasive or Non-Invasive

	Overall	ACP	No ACP	Invasive Procedure
Allergy skin prick testing	2	0	2	No
Bandage change	1	1	0	No
Blood draw	49	11	38	Yes
Botulin or Botox injection	26	2	24	Yes
Dilation/ eye drops	16	14	2	No
Discussion visit	17	12	5	No
Ear cleaning	1	1	0	Yes
EMG	1	1	0	Yes
Eye exam	19	17	2	No
Flu intranasal	1	0	1	No
Flu shot	9	2	7	Yes
G-Tube change	1	1	0	Yes
Hearing exam	1	1	0	No
Infusion	1	1	0	Yes
IV placement	1	1	0	Yes
Oral exam	2	2	0	No
Oral scope	1	1	0	Yes
Orthotics fitting	1	1	0	No
Other injections	1	1	0	Yes
Physical exam	22	21	1	No
Suture removal	1	0	1	No
Urodynamics	2	1	1	Yes
Vitals	10	8	2	No
X-Ray imaging	9	9	0	No

Note. ACP = Adaptive Care Plan; No ACP = No Adaptive Care Plan.

Table 4

Medical Professionals

	<i>n</i>	%
Advanced Practice Registered Nurse (APRN)	2	1.3
Medical Assistant/ Patient Care Assistant	57	35.6
Medical Doctor (including Fellow and Resident)	20	12.7
Ophthalmology Technician	19	17.3
Other*	8	5.1
Registered Nurse	52	32.9

**Note.* Other medical professionals included optometrist, phlebotomist, physician's assistant, x-ray technician, and x-ray technician trainee

Table 5

Means and Standard Deviations for the Total PRAP, PRAP Subscales, Parent or Legal Guardian Survey, and Medical Staff Survey

	Overall	ACP	No ACP
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>
Total PRAP	9.94 (2.55)	10.34 (2.72)	9.55 (2.29)
Communication	1.24 (.97)	1.14 (.96)	1.35 (.97)
Special Needs	1.31 (.55)	1.49 (.61)	1.14 (.41)
Anxiety and Coping	1.34 (.76)	1.36 (.66)	1.31 (.85)
Temperament	1.22 (.61)	1.45 (.61)	.99 (.52)
Parent Stress	.51 (.56)	.58 (.55)	.44 (.57)
Past Healthcare Encounter	1.54 (.65)	1.70 (.62)	1.38 (.64)
Invasiveness	1.53 (.86)	1.35 (.86)	1.70 (.83)
Developmental Impact	1.23 (.57)	1.21 (.59)	1.25 (.56)
Parent or Legal Guardian Survey	6.63 (.59)	6.67 (.61)	6.59 (.58)
Medical Staff Survey	6.82 (.30)	6.81 (.31)	6.82 (.29)

Note. ACP = Adaptive Care Plan; No ACP = No Adaptive Care Plan.

Table 6

*Bivariate Correlations Between Chronological Age of the Child with Total PRAP and PRAP**Subscale Scores*

	Overall	ACP	No ACP
Total PRAP	-.05	-.06	-.12
Communication	-.14	-.001	-.22*
Special Needs	.17*	.12	.10
Anxiety and Coping	.40	-.07	.16
Temperament	.20**	.21	.04
Parent Stress	.01	-.04	.01
Past Healthcare Encounter	.13	.003	.15
Invasiveness	-.17*	-.11	-.15
Developmental Impact	-.32***	-.19	-.46**

Note. ACP = Adaptive Care Plan; No ACP = No Adaptive Care Plan. * $p < .05$, ** $p < .01$, *** $p < .001$

Table 7

Means (Standard Deviations) and F-Values Associated with the Main Effect of Adaptive Care

Plan on PRAP Subscales After Controlling for Age of the Child

	ACP	No ACP	
	<i>M (SD)</i>	<i>M (SD)</i>	<i>F</i>
Communication	1.14 (.96)	1.35 (.97)	1.07
Special Needs	1.49 (.62)	1.14 (.41)	14.66***
Anxiety and Coping	1.36 (.66)	1.31 (.85)	0.05
Temperament	1.45 (.61)	.99 (.51)	21.98***
Parent Stress	.58 (.55)	.44 (.57)	0.12
Past Healthcare Encounter	1.70 (.62)	1.38 (.64)	8.60**
Invasiveness	1.35 (.86)	1.70 (.83)	4.84
Developmental Impact	1.21 (.59)	1.25 (.56)	0.29

Note. ACP = Adaptive Care Plan; No ACP = No Adaptive Care Plan. ** $p < .01$, *** $p < .001$

Table 8

Means (Standard Deviations) and F-Values Associated with the Main Effect of Invasiveness on PRAP Subscales

	Invasive	Not Invasive	
	<i>M (SD)</i>	<i>M (SD)</i>	<i>F</i>
Communication	1.30 (1.0)	1.17 (.93)	.15
Special Needs	1.19 (.45)	1.46 (.63)	1.04
Anxiety and Coping	1.47 (.84)	1.17 (.61)	10.11**
Temperament	1.04 (.56)	1.44 (.60)	3.92
Parent Stress	.42 (.52)	.62 (.59)	3.99
Past Healthcare Encounter	1.51 (.68)	1.58 (.63)	1.63
Invasiveness	1.87 (.80)	1.10 (.74)	33.28***
Developmental Impact	1.17 (.59)	1.31 (.55)	4.43

Note. ACP = Adaptive Care Plan; No ACP = No Adaptive Care Plan. ** $p < .01$, *** $p < .001$

Appendix A

Informed Consent

STUDY TITLE: The Use of Adaptive Care Plans for Children with Developmental Disabilities during Outpatient Clinic Appointments

STUDY NUMBER: 2017-1047

FUNDING ORGANIZATION: Department of Child Life & Integrative Care

Melissa R. Liddle, M.A.
Name of Principal Investigator

513-636-8989
Telephone Number

INTRODUCTION

We are asking for your permission for your child to be in a research study so that we can learn new information that may help others. If you decide not to give your permission for your child to be in this study, we will still take good care of him/her. If you decide to allow your child to be in this study, you may change your mind at any time during the study and your child can stop being in the study. Take all the time you need to make your choice. Ask us any questions you have. It is also okay to ask more questions after you decide to allow your child to be in the study. You can ask questions at any time.

WHY ARE WE DOING THIS RESEARCH?

In this research study we want to learn more about parents' perceptions of child life specialist support provided to their child during an outpatient appointment.

We are asking your child and other children with a developmental disability to be in the research, because your child currently has or would qualify for an adaptive care plan, which is an individualized approach to addressing challenges that children face during healthcare encounters.

WHO IS IN CHARGE OF THE RESEARCH?

Melissa Liddle, M.A. is the researcher at Cincinnati Children's Hospital Medical Center (CCHMC) that is in charge of this study.

WHO SHOULD NOT BE IN THE STUDY

Your child cannot be in this study if the parent or legal guardian is not 18 years of age or older or if the parent does not read or speak English.

WHAT WILL HAPPEN IN THE STUDY?

The research staff will explain each visit to you and may give you a handout that explains each visit in more detail. You will be able to ask questions to make sure that you understand what will happen to your child.

These are the things that will happen to your child while in the study:

Your child will be assigned to one of two groups, depending if your child has a current adaptive care plan. Your child will receive child life support based on information from your child's medical record during their appointment.

If you agree to allow your child to participate and your child qualifies for this study, the following tests and procedures will be performed:

- A. The child life specialist will support you and your child with the medical visit based off information from the electronic medical record. Your child will receive the usual standard of care.
- B. When the medical visit is over, you will complete a 7-question caregiver satisfaction survey.
- C. A medical professional will complete a 7-question satisfaction survey.
- D. The child life specialist will document in your child's electronic medical record, which is standard procedure.
- E. For the study, medical chart information will be reviewed.
- F. After your participation in the study, if your child does not have an adaptive care plan, then your child will be placed on the referral list.

Your child will be in the research study until after your child's outpatient appointment is finished.

WHAT ARE THE GOOD THINGS THAT CAN HAPPEN FROM THIS RESEARCH?

Being in this study may not help your child right now. When we finish the study, we hope that we will know more about the experience of children with developmental disabilities while attending medical appointments.

Potential benefits for your child may include less distress and increased coping during the healthcare visit. You may feel more satisfied with your visit. If your child does not currently have an adaptive care plan, your child can be placed on a referral list for these plans and contacted about it at a later time. The information learned from this research study may benefit other pediatric patients similar to your child.

WHAT ARE THE BAD THINGS THAT CAN HAPPEN FROM THIS RESEARCH?

There are no additional risks associated with involvement in this research study.

WHAT OTHER CHOICES ARE THERE?

Instead of being in this study, you can choose not to have your child be in it.

HOW WILL INFORMATION ABOUT YOUR CHILD BE KEPT PRIVATE?

Making sure that information about your child remains private is important to us. To protect your child's privacy in this research study we will:

- A. Make every effort to protect the privacy of the patients and their family.
- B. Access to the data collected with identifying information, will be limited to the primary researcher.
- C. Databases containing any information will require a password for access.
- D. Data sheets will be collected and stored in a secure manner for analyses and reporting.
- E. The research team will have access to the data only when individuals are identified by number and all personally identifying information is removed or excluded.
- F. The findings of this study will be reported in summary form only.
- G. Data and identifiers will be protected and destroyed after 6 years.

WHAT IF WE LEARN NEW INFORMATION DURING THE RESEARCH?

The study doctor will tell you if they find out about new information from this or other studies that may affect your child's health, safety or your willingness for your child to stay in this study.

WILL IT COST YOU ANYTHING EXTRA FOR YOUR CHILD TO BE IN THE RESEARCH STUDY?

Your/your child's insurance company will be responsible for the usual costs of his or her medical care, but you will not be charged any extra for participation in the research study.

WILL YOU/YOUR CHILD BE PAID TO BE IN THIS RESEARCH STUDY?

You will not receive reimbursement for your child's participation in this research study. A small toy will be given to all study participants.

WHAT HAPPENS IF YOUR CHILD IS INJURED FROM BEING IN THIS STUDY?

If you believe that your child has been injured as a result of this research you should contact Melissa Liddle as soon as possible to discuss the concerns. Treatment for injuries is available at CCHMC. If your child goes to the Emergency Room or to another hospital or doctor it is important that you tell them that your child is in a research study. If possible, you should give them a copy of this parental permission form.

CCHMC follows a policy of making all decisions about compensation for the medical treatment of physical injuries that happened during or were caused by research on an individual basis.

WHO DO YOU CALL IF YOU HAVE QUESTIONS OR PROBLEMS?

For questions, concerns, or complaints about this research study you can contact the study person listed on page 1 of this document.

If you would like to talk to someone that is not part of the research staff or if you have general questions about your research study rights or questions, concerns, or complaints about the research, you can call the CCHMC Institutional Review Board at 513-636-8039.

WHAT ELSE SHOULD YOU KNOW ABOUT THE RESEARCH?**AUTHORIZATION FOR USE/DISCLOSURE OF HEALTH INFORMATION FOR RESEARCH**

To be in this research study you must also give your permission (or authorization) to use and disclose (or share) your child's "protected health information" (called PHI for short).

What protected health information will be used and shared during this study?

CCHMC will need to use and share your child's PHI as part of this study. This PHI will come from:

- Your child's CCHMC medical records
- Your child's research records

The types of information that will be used and shared from these records include:

- Laboratory test results, diagnosis, and medications

- Reports and notes from clinical and research observations
- Imaging (like CT scans, MRI scans, x-rays, etc.) studies and reports
- If applicable, information concerning HIV testing or the treatment of AIDS or AIDS-related conditions, drug or alcohol abuse, drug-related conditions, alcoholism, and/or psychiatric/psychological conditions (but not psychotherapy notes).

Who will share, receive and/or use your child's protected health information in this study?

- Staff at all the research study sites (including CCHMC)
- Personnel who provide services to your child as part of this study
- Other individuals and organizations that need to use your child's PHI in connection with the research, including people at the sponsor and organizations that the sponsor may use to oversee or conduct the study.
- The members of the CCHMC Institutional Review Board and staff of the Office of Research Compliance and Regulatory Affairs.

How will you know that your child's PHI is not misused?

People that receive your child's PHI as part of the research are generally limited in how they can use your child's PHI. In addition, most people who receive your child's PHI are also required by federal privacy laws to protect your child's PHI. However, some people that may receive your child's PHI may not be required to protect it and may share the information with others without your permission, if permitted by the laws that apply to them.

Can you change your mind?

You may choose to withdraw your permission at any time. A withdrawal of your permission to use and share your child's PHI would also include a withdrawal from participation in the research study. If you wish to withdraw your permission to use and share your child's PHI you need to notify the study doctor, listed on the first page of this document, in writing. Your request will be effective immediately and no new PHI about your child will be used or shared. The only exceptions are (1) any use or sharing of PHI that has already occurred or was in process prior to you withdrawing your permission and (2) any use or sharing that is needed to maintain the integrity of the research.

Will this permission expire?

Your permission will expire at the end of the study. If the study involves the creation or maintenance of a research database repository, this authorization will not expire.

Will your child's other medical care be impacted?

By signing this document, you agree for child to participate in this research study and give permission to CCHMC to use and share your child's PHI for the purpose of this research study. If you refuse to sign this document your child will not be able to participate in the study. However, your child's rights concerning treatment not related to this study, payment for services, enrollment in a health plan or eligibility of benefits will not be affected.

SIGNATURES

The research team has discussed this study with you and answered all of your questions. Like any research, the researchers cannot predict exactly what will happen. Once you have had enough time to consider whether your child should participate in this research you will document your permission by signature below.

You will receive a copy of this signed document for your records.

Printed Name of Research Participant

Signature of Research Participant
Indicating Consent or Assent

Date

Signature of Parent or Legally Authorized
Representative*

Date

* If signed by a legally authorized representative, a description of such
representative's authority must be provided

Signature of Individual Obtaining Consent

Date

Appendix B

Parent or Legal Guardian Survey

A child life specialist helped your child during their visit today. A child life specialist is trained to help children cope with any stress they may experience during a hospital stay or health care visit.

A child life specialist:

- Uses play or discussion to teach what will happen
- Explains treatments, tests, and procedures in a way that makes sense to the child
- Helps parents or legal guardians understand changes in behavior they may notice and find ways to help
- Practices ways to cope with what is happening
- Helps children to express their feelings

Please read the following statements about your child's appointment and select the best response.

1. I would recommend a child life specialist to help other children with their health care visits.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
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2. The child life specialist provided highly individualized care that met my child's medical needs.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
----------------------	--------------------	----------------------	-------------------------------	-------------------	-----------------	-------------------

3. My child coped or handled his or her visit today to the best of their abilities.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
----------------------	--------------------	----------------------	-------------------------------	-------------------	-----------------	-------------------

4. Without a child life specialist in the room, today's visit may have been longer.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
----------------------	--------------------	----------------------	-------------------------------	-------------------	-----------------	-------------------

5. My child was comfortable during his or her visit today.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
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6. My child had a positive experience because of the help provided by the child life specialist.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
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7. Overall, I find value in what the child life specialist did for my child during our visit.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
----------------------	--------------------	----------------------	-------------------------------	-------------------	-----------------	-------------------

8. I would NOT recommend a child life specialist to help other children with their health care visits. (-)

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
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*Note. (-) indicates a negatively keyed item

Appendix C

Medical Staff Survey

This patient had a child life specialist assist with her or his appointment today. A child life specialist is trained professional whose job is to help children cope with being in the hospital and with other stressful events.

Please read the following statements about your patient's appointment and select the best response.

A child life specialist:

- Uses play or discussion to teach what will happen
- Explains treatments, tests, and procedures in a way that makes sense to the child
- Helps parents or legal guardians understand changes in behavior they may notice and find ways to help
- Practices ways to cope with what is happening
- Helps children to express their feelings

1. I would recommend a child life specialist to help other children with their health care visits.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
----------------------	--------------------	----------------------	-------------------------------	-------------------	-----------------	-------------------

2. The child life specialist provided highly individualized care that met the child's medical needs.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
----------------------	--------------------	----------------------	-------------------------------	-------------------	-----------------	-------------------

3. This child coped or handled his or her visit today to the best of his or her abilities.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
-------------------	-----------------	-------------------	----------------------------	----------------	--------------	----------------

4. Without a child life specialist in the room, today's visit may have been longer.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
-------------------	-----------------	-------------------	----------------------------	----------------	--------------	----------------

5. This child had a positive experience because of the help provided by the child life specialist.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
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6. This child had a better experience because of the help provided by the child life specialist.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
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7. Overall, I find value in what the child life specialist did for this child during his/her visit.

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
-------------------	-----------------	-------------------	----------------------------	----------------	--------------	----------------

8. I would NOT recommend a child life specialist to help other children with their health care visits. (-)

Strongly Disagree	Mostly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Mostly Agree	Strongly Agree
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9. I am a/an:

☐ APRN ☐ MA/PCA ☐ MD ☐ OrthoTech ☐ RN

☐ Other: _____

*Note. (-) indicates a negatively keyed item

Appendix D

Psychosocial Risk Assessment in Pediatrics

This is a copyrighted measure and is not reproduced here. Information about accessing the measure can be found at: <https://praptool.com/> .

Appendix E

Adaptive Care Plan Template

Name:**MRN:****Date of Birth:****Adaptive Care Plan: Individualizing Healthcare for Patients with Developmental and Behavioral Challenges****ACT Recommendations:****Indicated stress level based on Psychosocial Risk Assessment in Pediatrics:**

0-7=Level 1 (low risk) 8-14= Level 2 (moderate risk) 15-24= Level 3 (high risk)

Area/Procedure PRAP Level PRAP Score PRAP ID Date Completed**Special needs description:****Describe past healthcare experiences:**

-Difficult clinics include:

-Difficult parts of exam include:

Stressors and the reactive behaviors:

-Stressors include:

-Reactive behaviors include:

-Comforting measures include:

Temperament:**Communication information:**

-Communicates wants and needs through:

-Receptively benefits from the use of:

Sensory information:

-Pt is sensitive to:

Pain responses:**Interests/Motivators:****Additional considerations:**

Signature/Credentials:

Pager:

Date:

Summary

Title: Effectiveness of Adaptive Care Plans for Children with Developmental Disabilities During Outpatient Clinic Appointments

Problem. According to the Centers for Disease Control and Prevention (2015), one in six children have one or more than one developmental disability. Many children with developmental disabilities have co-occurring medical conditions requiring visits to medical providers, but also demonstrate problematic behaviors and struggle to cooperate with these healthcare experiences (Bultas et al., 2016; Schieve et al., 2012). Adaptive care plans take a family-centered approach to healthcare by identifying specific challenges that a child encounters during healthcare in order to reduce the harmful effects of medical experiences (Liddle et al., 2018). Although adaptive care plans have been implemented for nearly 10 years, few studies have evaluated the effectiveness of these plans (Balakas et al., 2015; Broder-Fingert et al., 2016; Wittling et al., 2018). Therefore, this dissertation examined if adaptive care plans positively affect the psychosocial outcomes among children with developmental disabilities, and greater parent or legal guardian and medical staff satisfaction with the healthcare visit, compared to children with developmental disabilities who do not have adaptive care plans.

Method. One-hundred and sixty children between 3 and 18 years of age with developmental disabilities and their parents or legal guardians (child's $M_{\text{age}} = 8.10$, $SD = 3.75$) were enrolled from outpatient clinics at a large, pediatric medical center. For children with adaptive care plans, child life specialists provided interventions based on information from existing adaptive care plans. After each child's medical experience, parents or legal guardians and medical staff completed the Parent or Legal Guardian Survey and the Medical Staff Survey, respectfully. Additionally, the child life specialist completed the Psychosocial Assessment in Pediatrics (PRAP; Staab et al., 2013). Each child's parent or legal guardian provided consent to participation in the study prior to the medical encounter.

Findings. Children with adaptive care plans were perceived to have higher total psychosocial distress, have a greater number of mental, physical, developmental, behavioral, and psychological challenges that affected their healthcare experience, be less adaptable during the healthcare encounter, and have experienced a higher number of difficult past healthcare encounters that impacted their coping. Both the parents or legal guardians of children with developmental disabilities and the medical staff caring for children with developmental disabilities did not perceive adaptive care plans as positively effecting healthcare encounters.

Implications. The current research informs future research directions related to interventions for children with developmental disabilities undergoing healthcare experiences and the effectiveness of adaptive care plans. Future research is needed to understand if adaptive care plans reduce psychosocial distress during and after medical procedures, and if children who have specific types of developmental disabilities experience greater benefit from these plans.

Press Release

A recent study examined the effectiveness of a novel approach to improving healthcare experiences for children with developmental disabilities. Adaptive care plans are individualized, patient-centered treatment plans intended to enable positive healthcare experiences for children with developmental disabilities. Adaptive care plans are developed through collaboration between caregivers of children with developmental disabilities and medical staff in order to anticipate the psychosocial challenges that may be experienced by children with developmental disabilities in healthcare settings. Lead researcher, Melissa Liddle, explained that counter to her expectations, children with developmental disabilities who had adaptive care plans were perceived to have higher total psychosocial distress, have a greater number of mental, physical, developmental, behavioral, and psychological challenges that affected their healthcare experience, be less adaptable during the healthcare encounter, and have experienced a higher number of difficult past healthcare encounters that impacted their coping compared to children with developmental disabilities who did not have adaptive care plans. Furthermore, parents and healthcare professionals did not perceive adaptive care plans to positively effect healthcare encounters. Unlike previous studies, the current research does not demonstrate that adaptive care plans are effective for children and adolescents with developmental disabilities who struggle to cope with healthcare encounters. Future research should continue to evaluate the effectiveness of adaptive care plans using alternative research methods and explore other systems that provide accommodations to children with developmental disabilities that enable productive medical experiences.