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# Evaluation of a Coping Kit of Items to Support Children with Developmental Disorders in the Hospital Setting

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# Evaluation of a Coping Kit for Children With Challenging Behaviors In a Pediatric Hospital

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**T**he Centers for Disease Control and Prevention (CDC) (2004) defines developmental disabilities as a diverse group of severe chronic conditions that are due to mental and/or physical impairments that affect language, mobility, learning, self-help, and independent living. These disabilities may include autism spectrum disorder (ASD), cerebral palsy, Down syndrome, and other congenital abnormalities, vision and hearing impairments, and intellectual disabilities. They are estimated to affect 17% of children less than 18 years of age in the United States (CDC, 2006).

Although research has shown that individuals with developmental disabilities have more hospital admissions than non-developmentally delayed children (Liptak, Stuart, & Auinger, 2006; Peterson, Ross, & Tucker, 2002; Scarpinato et al., 2010; Souders, Freeman, DePaul, & Levy, 2002), there is little research describing what forms of distraction work well for them when they are in health care settings. Convincing a child to cooperate during a health care visit can be difficult and is often a trial and

This study attempted to answer the question, "Do nurses perceive coping kits to be effective at meeting the needs of hospitalized children with developmental disabilities who are at increased risk for challenging behaviors?" A cross-sectional post-test survey study design was used, with a convenience sample of 24 registered nurses at a Midwestern free-standing children's hospital. A coping kit with simple communication cards, social script book, and distraction items (toys) was developed to enhance communication and distract children with developmental disabilities (including autism spectrum disorder) undergoing procedures in the hospital. A modified version of Hudson's (2006) intervention effectiveness survey was used to measure the nurse's perception of the effectiveness of the coping kit. Nurses perceived the coping kits to be effective for decreasing their patient's anxiety, calming the child's behavior, and increasing cooperation during procedures. The nurse can develop a plan of care that includes a coping kit to help gain cooperation with the hospitalized child with challenging behaviors.

error process (Hudson, 2006). Challenging behaviors for children may result (Debbaudt, 2009). Clinical practice articles report the use of communication tools and adaptive items helpful in gaining the cooperation of children with the developmental disability ASD and the accompanying behavioral challenges (Browne, 2006; Souders et al., 2002). However, communication tools and items in a coping kit are an extra expense, and providing evidence that the cost of the coping kit is justified by the benefits to staff and patients is important.

## Purpose

The purpose of this study was to evaluate the nurse's perception of the effectiveness of a coping kit intervention. The research question was: "Do nurses perceive coping kits effective at meeting the needs of hospitalized children with developmental disabilities who are at increased risk for challenging behavior?" The study was framed on Bandura's (1977) self-efficacy theory. Self-efficacy is defined as a person's belief in his or her ability to perform a designated task (Bandura, 1977). Nurses would need to perceive that the items in the kit were useful

for improving communication, providing distraction, and decreasing a child's anxiety and challenging behaviors to justify their use the kit in the future.

## Significance and Rationale

### Behavioral Challenges In the Hospital

Research has demonstrated that children with ASD suffer great anxiety with changes in routine environment. Therefore, ASD is recognized as the most severe developmental disability in terms of behavioral challenges (Gurney, McPheeters, & Davis, 2006; Newsom & Hovanitz, 2006). Challenging behaviors accompany the child's impaired social interaction and communication (American Psychiatric Association [APA], 1994). Children with ASD struggle with routine changes and new environments (Souders et al., 2002). Although children with ASD have similar basic medical needs as children without any developmental disabilities, meeting their needs can be more challenging (Myers & Johnson, 2007), particularly in the unfamiliar hospital environment (Scarpinato et al., 2010).

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Children with developmental disabilities need time to become familiar with their environment. Communication must be kept simple to allow the patient to feel comfortable and safe within the new environment (Debbaudt, 2009; Myers & Johnson, 2007; Scarpinato et al., 2010). Without this focus, many aspects of the health care setting can cause a great deal of stress and anxiety for this population of children (Debbaudt, 2009; Souders et al., 2002).

One negative experience can adversely affect the child's behavior at future visits; therefore, it is important that nurses use strategies proactively to prevent challenging behaviors at the onset of every health care visit (Peterson et al., 2002; Souders et al., 2002). Further, it is critical that nurses use creativity, sensitivity, and awareness when working with families of children with developmental disabilities, and recognize the value of the parents' expertise (Golnik & Maccabee-Ryaboy, 2010; Inglese, 2009; Raposa, 2009; Souders et al., 2002).

Effective training programs in behavior management skills are often unavailable for nurses within hospitals (Tucker, Derscheid, Odegarden, & Olson, 2008). The assumption may be that nurses have these skills innately either from schooling or experience, but this is rarely the case (Tucker et al., 2008). Instead, nurses are challenged with supporting these children, and lack of training, time, and resources only seem to exacerbate these obstacles.

Nurses are challenged by time constraints (Tucker & Spear, 2006), and learning how to use items in a kit takes time. Effort is also required to locate and retrieve kits from storage. Therefore, it is important that the nurse believes the items in the kit will be useful in providing a positive experience for children with developmental disabilities to make the time and effort worthwhile. Children with developmental disabilities, families, and care providers alike are stressed when in the hospital (Scarpinato et al., 2010). Staff must be committed to use the kits and understand that the time invested in retrieving and using the items will make both the child's and staff's experience less stressful.

### Anticipatory Guidance

Research has shown that with anticipatory guidance, anxiety for

typically developing children and their families can be reduced in the health care setting (Kain et al., 2007). Increased anxiety in the hospital is related to adverse post-operative outcomes, including delirium, pain, narcotic use, sleep problems, delayed return to activities of normal living, maladaptive behaviors, and ultimately delays in recovery (Kain et al., 2007; Kain, Mayes, Caldwell-Andrews, Karas, & McClain, 2006). However, with family-centered preparation, children experienced significantly less anxiety, less analgesic consumption, and decreased time until discharge (Kain et al., 2006). This improvement in the child's adjustment consequently reduced parental anxiety throughout the process (Kain et al., 2006). Other sources of anxiety in the health care setting include changes in routine, new faces, painful procedures (starting IVs and inserting nasogastric tubes [NGs]), lack of sleep, and privacy. Although the traditional thought has been that children can be effectively supported during procedures with medication, researchers have found that using a behaviorally based and supportive program had results equal to using pharmacological interventions (Kain et al., 2006). Although the above studies involve children with typical development, anticipatory guidance merits consideration for children with developmental disabilities, including ASD, as well.

### Communication

Even rote activities within the health care setting, such as obtaining vital signs and performing a physical examination, can be arduous for children with developmental disabilities (Souders et al., 2002). However, if sufficient and appropriate communication and distraction are provided, children can become calmer and more cooperative in these new and stressful situations (Souders et al., 2002). Finding a means to communicate with children with developmental disabilities is critical to caring for them safely in the hospital setting. Browne (2006) recommends that nurses should talk to parents to determine how the child communicates and what triggers challenging behaviors. With improved communication, children may display less challenging behaviors that stem from frustration and sensory overload (Debbaudt, 2009; Nind & Kellett, 2002). Further, identifying the source of the aggrava-

tion and altering that source may decrease patient anxiety, and ultimately, the challenging behavior (Carbone, Farley, & Davis, 2010; Debbaudt, 2009; Hanley, Iwata, & McCord, 2003).

### Coping Kits

Written schedules, social stories, sensory regulation items, sensory input activities (such as watching something spin, holding and manipulating an item with hands, or mouthing an item) can help children relax (Hudson, 2006). Other techniques found to be helpful in assisting communication and decreasing anxiety include picture exchange systems, family presence, and social stories (Browne, 2006; Gray, 1994; Kain et al., 2007; Scattone, Wilczynski, Edwards, & Rabian, 2002; Tucker & Spear, 2006). Picture exchange systems are picture cards that increase communication and enhance development by giving children a tool with which they can initiate communication and make their needs known (Browne, 2006). Additionally, research has found that negative behavior, such as running out of the room, may be prevented with attention, such as family presence and access to positive items (rewards) (Tarbox, Wallace, & Williams, 2003).

Research indicates that the use of social stories can help reduce behavioral disruptions for children with ASD (Kokina & Kern, 2010; Scattone et al., 2002). Social stories are written to break down a complicated abstract procedure, such as having an electroencephalogram (EEG), into smaller parts. Social expectations are described, including what might happen during the test. Social stories have been identified as a tool that can help create a routine and familiarity with a new situation to which children with ASD may be exposed (Scattone et al., 2002). While collaboration with parents is regarded as one of the most important ways to support children with behavioral challenges (Inglese, 2009; Souders et al., 2002), there may also be a role for distraction in the form of a coping kit that includes social stories, communication cards/devices, and sensory items (see Figure 1) (Golnik & Maccabee-Ryaboy, 2010).

### Methodology

A posttest design was employed in this study. Institutional Review Board

**Figure 1.**  
**Coping Kit**



approval was obtained. Trained research assistants approached nurses in the identified hospital units and explained the coping kit intervention. Instructions on the use of the kit were included in the kit on a Health Facts teaching sheet. Attached to the kit was an instruction card on how to log into Survey Monkey™ to complete a post-intervention survey. The nurse filled out an online survey that consisted of 9 demographic questions and 16 intervention effectiveness questions, taking approximately 10 to 15 minutes to complete. The intervention effectiveness questions were based on an intervention effectiveness questionnaire described in Hudson (2006). Additionally, the nurses were questioned about the context for which the coping kit was used. The choices for the response to this question were a) distraction during a procedure, b) communication to prepare for a procedure, or c) other (asked to specify what the other situation entailed). The study questionnaire asked the user to rate the value of an intervention with a yes, no, or N/A format. There also was a free text section for each question that allowed the nurse to give suggestions on improving the kit, explaining how the kit is effective in a particular situation and to give suggestions on changing the contents of the kit.

### Sample

Participants were recruited by convenience sampling from three inpatient units and the Emergency Room. These units were selected

because children with behavioral challenges are most likely seen on these units. No prior study with the same variables for parents of children with ASD is available for reference in terms of a sample size. The researchers anticipated enrolling 60 nurses, 15 from each unit, out of a total of approximately 1200 nurses employed within the hospital. However, the project was stopped after the enrollment of 24 participants over five months' time. The initial feedback was positive, and the hospital child life department budgeted the \$35 estimated coping kit cost going forward. The research study co-investigators – two staff nurses, a child life specialist, and an advanced practice nurse – recruited the participants.

Nurses on these units had previously completed a behavioral-challenges, instructor-led, one-hour class where they were taught techniques to better support families of children with behavioral challenges while in the hospital. The nurses were notified at the beginning of the study about the availability of the coping kits, and upon request, were provided a brief in-service about their use by the co-investigators. The nurses could then identify a child who they felt would benefit from the kit. After the child used the kit, the nurse completed the online survey.

Inclusion criteria for this study included prior nursing experience caring for a child 2 to 18 years of age with a developmental disability, such as ASD, Down syndrome, other developmental disability, or other neuro-

logical condition. Use of kits on children without developmental disabilities or neurological impairment was excluded. The child's diagnosis was not confirmed for the study. A notation in the chart that the child had such a diagnosis was regarded as meeting the inclusion criteria.

### Instrument

Hudson's (2006) intervention effectiveness survey was modified with permission to evaluate the coping kit. The tool was a checklist of 16 "yes" or "no" questions. Modifications included adding a "not applicable" option and a free text section to gain further explanation about the nurse's perception of the value of the coping kit. An additional question asked nurses if there were other items they would like to add or remove from the kit.

### Description of the Coping Kit

The coping kit (see Figure 1) was composed of simple communication cards, a social script book about going to the hospital, distraction items (toys), a pad of paper and a pencil, a picture communication card set on a ring, and a piece of thera-tubing to play with or chew. The child could keep these items. Additional reusable items were part of the kit for the child's use while at the hospital. These included a large rubber ring to chew on or play with, a squidy ball, a light up spinning fan, and a baby buzzer-vibrating face-shaped toy with a mirror on one side. Both the nurse and parents were given written instructions for use of the kit. The instructions included supervising the child while using the kit.

### Data Collection and Analysis

Participants completed the questionnaire on the Survey Monkey Web site that was linked to the facility's clinical research Intranet page. They were encouraged to complete the survey during the shift in which the kit was used whenever possible. Analysis included descriptive statistics (frequencies and ranges) for demographics and the survey results, which were evaluated through Survey Monkey and Excel.

### Results

#### Demographics

Twenty-four nurses participated in the study (see Table 1). The majority of the nurses were female ( $n = 17$ ,



**Table 1.**  
**Demographics**

Nurse ( <i>n</i> = 24)	<i>n</i> (%)
<b>Gender</b>	
Male	7 (29.2)
Female	17 (70.8)
<b>Age (Years)</b>	
21 to 30	11 (45.8)
31 to 40	8 (33.3)
41 to 50	4 (16.7)
Older than 50	1 (4.2)
<b>Highest Degree</b>	
Associate's degree	1 (4.2)
Bachelor's degree	21 (87.5)
Master's degree	2 (8.3)
<b>Nursing Experience (Years)</b>	
Less than 1	2 (8.3)
1 to 2	2 (8.3)
2 to 5	8 (33.3)
5 to 10	4 (16.7)
More than 10	8 (33.3)
<b>Nursing Unit</b>	
Emergency department/trauma center (EDTC)	8 (33.3)
Neuroscience	6 (25.0)
Medical floor	3 (12.5)
Other	7 (29.2)
<b>Child (<i>n</i> = 24)</b>	
<b>Age (Years)</b>	
Younger than 3	1 (4.2)
3 to 5	10 (41.7)
6 to 11	8 (33.3)
Older than 11	5 (20.8)
<b>Diagnosis</b>	
Autism spectrum disorder (ASD)	12 (50.0)
Down syndrome	1 (4.1)
Head injury	1 (4.1)
Other	10 (41.8)

70.8%), bachelors' prepared (*n* = 21, 87.5%), with two or more years of nursing experience (*n* = 20, 83.7 %). One-third worked in the emergency department trauma center (EDTC) (*n* = 8, 33.3%). Eleven nurses (45.8%) were between 21 to 30 years of age. The age

of the child for whom the kit was used was fairly well-distributed between preschool-aged, school-aged, and teenage children. Only 1 (4.2%) kit was used on a child younger than three years old. The majority of children (*n* = 12, 52.2%) had a diagnosis of ASD, one child (4.3%) had a head injury, and the remaining 9 (39.1%) had other developmental disabilities (developmental delay/non-verbal [*n* = 4], global developmental delay [*n* = 2], cerebral palsy secondary/near drowning [*n* = 1], Rett syndrome [*n* = 1], agitation secondary to Ativan (Lorazepam) at another facility [*n* = 1]).

### Context of Use

Nurses responded that the kit was used for distraction during a procedure (50%), communication to prepare for a procedure (4.2%), and for other uses (50%). Other uses that nurses identified included anxiety reduction due to diagnosis or multiple hospitalizations, general distraction, or distraction while performing vital signs and assessments. Results of the coping kit effectiveness survey are listed in Table 2.

### Discussion and Practice Implications

The purpose of this study was to evaluate the nurse's perception of the effectiveness of a coping kit intervention for children with developmental disabilities with the potential for challenging behaviors in the health care setting. Overall, staff found kits to be effective for distraction before or during a procedure, but not as useful communication to prepare for a procedure.

The majority of the time (*n* = 22, 91.7%) parents were present during the kit's use, and in many cases, staff indicated in their comments that the parent was eager to use the items. Collaboration with parents is recognized as the most important way to support children with challenging behaviors (Browne, 2006; Inglese, 2009; Souders et al., 2002). Parents know how their child communicates and what triggers challenging behaviors.

Only 4 (16.7%) nurses stated that the kits helped the child follow steps to a procedure and understand expectations. Nine nurses (37.5%) indicated that the kit helped the child cooperate with requests made. Distraction helps children, but there appears to be a need for other strategies for

preparing patients for procedure in addition to the distraction (Browne, 2006; Hudson, 2006). Many comments specific to these questions stated that the child was nonverbal and unable to follow directions due to their developmental level. However, one nurse indicated, "Patient needed an IV and EEG leads placed. Patient was able to hold still for both procedures." Seeing the child cooperate with the use of distraction dispelled the nurse's assumption that the patient would not be able to lie still for the procedure. In fact, 12 (50%) nurses believed that the coping kit increased the child's willingness to participate in a procedure. Overall, 19 (79.2%) nurses believed that the kit increased the child's coping and that the child responded positively to the intervention, one nurse stating simply, "It distracted him."

Most (*n* = 19, 79.2%) nurses indicated that a change in the child's behavior was noticeable after given items from the coping kit. Nurses found parents were receptive to the kit items. The most useful items for distracting the child were the chewable toys and the light-up spinning fan toy. Sturdy, safe, chewable toys and fans are considered to be sensory items. Children may seek oral input from chewing the item or watching it spin, which in turn, calms the child (Golnik & Maccabee-Ryaboy, 2010). A calmer child may help decrease the anxiety of the nurse caring for the child as well. Nurses in the present study commented that the child showed "very decreased anxiety noted by myself and mom" and "noticed that the patient was eager to see what was in the kit." Other comments included: "Shortly after [I] saw patient playing with the toys that were in the kit – it seemed to ease the patient's mind and kept him distracted," and "lots of chewing, calmer, able to play with other toys while chewing." In a few cases, staff indicated that the distraction was temporary, and the child seemed to grow bored with the items. This finding suggests that distraction items are only useful for short procedures.

Nurses found the communication items (paper, pencil, and communication cards on the ring) in the coping kits helped them effectively communicate with the child. Nurses used the paper to create a schedule for the child. The nurses pointed at items on the cards, and some children were able

**Table 2.**  
**Survey Results**

Question	Yes n (%)	No n (%)	N/A n (%)	Comments
Were parents or guardian present during use of coping kit?	22 (91.7)	2 (8.3)	0 (0)	Parents receptive. Child chewed on items.
Was change in child's behaviors noticeable after given items from the kit?	19 (79.2)	5 (20.8)	0 (0)	Very decreased anxiety noted by myself and mom. Noticed that the patient was eager to see what was in the kit. Shortly after saw patient playing with the toys that were in the kit. It seemed to ease the patient's mind and kept him distracted. Lots of chewing, calmer, able to play with other toys while chewing.
Was the child able to follow steps of the procedure?	4 (16.7)	12 (50)	8 (33.3)	Non-verbal, delayed.
Did the child appropriately use items in the coping kit?	22 (91.7)	1 (4.2)	1 (4.2)	Liked light up toy.
Did the child spontaneously use items in the coping kit?	11 (45.8)	10 (41.7)	3 (12.5)	Placed in hand. Liked light up toy.
Did the coping kit intervention decrease the child's anxiety level?	17 (70.8)	7 (29.2)	0 (0)	Hard to tell. Something to focus on. Not anxious to begin with.
With the coping kit, did the child cooperate with requests made?	9 (37.5)	7 (29.2)	8 (33.3)	Developmental delay – Unable to follow directions.
Do you think the coping kit intervention increased the child's willingness to participate in a procedure?	12 (50)	4 (16.7)	8 (33.3)	Good for distraction. Patient needed an IV and EEG leads placed. Patient was able to hold still for both procedures.
Did the kit help the child cope?	19 (79.2)	1 (4.2)	4 (16.7)	Good for distraction. Hard to assess because of developmental level.
Did the items in the kit help the child understand expectations?	4 (16.7)	12 (50)	8 (33.3)	Too young to understand. Developmental delay so can't understand.
Did the child respond positively to the intervention?	19 (79.2)	0 (0)	5 (20.8)	Played with toys.
Was the stress of medical personnel lessened during the interaction in which the coping kit was used?	15 (62.5)	5 (20.8)	4 (16.7)	Gave child something to do with hands. One more thing to remember to use, and find. Working with autistic children in the EDTC is very stressful for the staff especially when there are tasks to be done in a timely manner.
Did medical personnel effectively communicate with the child to reach attempted goal?	15 (62.5)	1 (4.2)	8 (33.3)	Goal to calm child. Patient is non-verbal and does not understand staff.
Did medical personnel give information in a timely, supportive manner?	18 (75.0)	0 (0)	6 (25.0)	Communicated with parents at time of admission, proactive rather than reactive.
Did the child transition with ease with the use of the coping kit?	17 (70.8)	4 (16.7)	3 (12.5)	Child was happy and playful all shift.
Was the child able to communicate needs to the medical personnel?	4 (16.7)	13 (54.2)	7 (29.2)	Non-verbal child, no specific thing needed to be communicated by patient at this time. Not able to use the flip card.
Are there other items you would like to add or remove from the kit?	2 (8.3)	22 (91.7)	0 (0)	Add more interesting and distracting toys. Spinning light up toy not for children with seizures.

to understand expectations based on the communication tool. Twenty-two (91.7%) nurses stated that the child used the items in the kit appropriately. Eleven (45.8%) children used the items in the coping kit spontaneously, and 17 (70.8%) nurses indicated they perceived the kit decreased the child's anxiety level. Further, 18 (75%) nurses indicated they were able to give information in a timely, supportive manner. No participants disagreed with this question. One nurse commented, "Communicated with parents at time of admission, proactive rather than reactive." These findings match the research findings by Souders et al. (2002), as well as the opinion article by Debbaudt (2009), who found that if sufficient communication and distraction are provided, children can become calmer and more compliant in stressful situations. Nurses in the present study were able to use the kit to help the child transition with ease in 17 (70.8%) cases; however, only 4 (16.7%) believed the kits helped the child communicate needs to the medical personnel. This finding suggests that coping kits may be only one part of a package of interventions for children with communication issues that place them at risk for challenging behaviors when stressed.

Fifteen (62.5%) nurses indicated that stress was lessened during the interaction in which the kit was used. One nurse commented, "Working with autistic children in the EDTC is very stressful for the staff, especially when there are tasks to be done in a timely manner." This comment highlights the stress nurses are under to complete procedures in a timely manner. Tucker and Spear (2006) concur that nurses are stressed by time constraints. A coping kit is a useful strategy to improve a child's cooperation. The time spent retrieving the kit may be less than the time it would have taken to gain a child's cooperation without the kit. Ancillary staff can assist in the retrieval. Kits can be kept in a convenient location on the unit to minimize time in kit retrieval.

Few kits were used for procedural preparation. However, there is a critical need to help support a child during a procedure. Much of the current evidence indicates that preparation is key (Kokina & Kern, 2010; Scattone et al., 2002); thus, more effort is needed to explore what other methods would assist nurses in preparing children for

procedures. It is important to find effective ways to support children with behavioral challenges while in the hospital. The present study findings suggest that a coping kit may be a part of a package of interventions to help alleviate anxiety for the hospitalized child with behavioral challenges.

Nurses who have had some education in the use of a coping kit may be able to better support children with developmental disabilities who have unique needs. Meeting these needs may reduce child anxiety thought to be antecedent to challenging behavior. Helping the child will not only ease the experience of the child in the hospital, but also serve as a role model for parents and children alike (Tucker et al., 2008). This study evaluated the use of such a kit for the nurses' perception of its effectiveness for supporting children with developmental disabilities who are prone to challenging behaviors.

### Study Limitations

This study only captured the experience and opinion of a small sample of nurses in one facility. Quantitative tools were not used to measure anxiety or behaviors. The diagnosis of ASD or other developmental disability was not verified with a diagnostic tool. Generalizability is therefore limited. The questionnaire was modified to include a free-text section, and no validation was possible.

### Future Research

Future research needs to focus on the experiences of families with hospitalized children with challenging behaviors, explore the use of items (such as procedure-specific social scripts in procedural preparation), and investigate other supportive interventions. A behavioral observation tool is also needed as an objective measure of a child's behaviors.

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continued on page 221

## Evaluation of a Coping Kit

continued from page 220

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