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Social Script iPad Application Versus Usual Care Before Undergoing Medical Imaging: Two Case Studies of Children with Autism

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Abstract

Autism spectrum disorders (ASDs) are neurodevelopmental disorders of socialization, communication, and repetitive behaviors. Children with ASD have underlying anxiety leading to challenging behaviors in unfamiliar situations. The anxiety impacts timely completion of an imaging procedure. The purpose of the case study was to describe the process of the social script intervention delivered using the iPad application on parent and child anxiety, child behaviors, and imaging procedure length between two

parent and child dyads. The case study of two parent-child dyads demonstrated the process for comparing the social script intervention iPad app for preparing for imaging versus usual care. Parent anxiety decreased more for the parent with the intervention. Computerized tomographic scan length of time to hold still decreased more for child with the intervention. There were fewer challenging child behaviors for child with the intervention. The results guide development of larger study, with the potential to mitigate the negative experiences for a child with ASD and the family during imaging.

Keywords

Autism, Radiology case report, Anxiety

Introduction

Autism spectrum disorder (ASD) is prevalent in approximately 1 of every 88 people in the United States (Centers for Disease Control and Prevention, 2012). According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association [APA], 2013), children with ASD exhibit (1) impairments with social interaction and social communication and (2) restricted interests and repetitive behaviors. These symptoms affect both the child, who may experience anxiety and trouble cooperating, and their parent, who may experience anxiety during medical imaging (e.g., X-rays and computerized tomographic [CT] scans; Davis et al., 2011, de Andres-Garcia et al., 2013, Lovell et al., 2012, Peacock et al., 2012). Health-care providers (HCPs) find it difficult to complete imaging for children with ASD who are anxious and have trouble cooperating (Johnson & Rodriguez, 2013). With the large population of children with ASD, strategies to improve the imaging experience for the child and the parent are essential to timely and safe completion of imaging.

Previous studies indicate that children with ASD have different needs when being prepared to undergo a medical procedure, based on their level of development not their age (Koller and Goldman, 2012, Scarpinato et al., 2010). Imaging procedure preparation for typically developing children involves instruction “tools and tips” such as informational brochures, tours, coloring pages, and accurate information, selected based on a child's age (Metzger, Mignogna, & Reilly, 2013). However, children with ASD have distinct needs for procedure preparation that do not follow the age criteria of a typically developing child as a result of their sensory, communication, and social challenges (Johnson & Rodriguez, 2013). For example, unplanned medical procedures in an unfamiliar setting with HCPs unfamiliar with the child can provoke challenging behaviors, resulting in increased anxiety and distress for the parent and child, prolonged procedure times, increased costs, and poorer health-care outcomes (Liptak et al., 2006, Lokhandwala et al., 2012). Moreover, behavioral problems can affect the imaging quality (Nordahl et al., 2008), delay or prolong imaging, and may even necessitate sedation, physical restraints, or canceling imaging procedures (Netzke-Doyle, 2010). Children with ASD could benefit from learning special coping strategies during procedure preparation by the HCP to be able to complete imaging.

Many studies report on the use of social stories™ as a strategy to help children cope with the stress of unfamiliar surroundings, people, and expectations for cooperation in nonmedical settings (Dodd et al., 2008, Kokina and Kern, 2010, Koller and Goldman, 2012, Reichow and Sabornie, 2009). A social story is a script written from the child's perspective, with photographs and words that provide a description about a procedure in a step-by-step approach (Gray, 2003). A social story helps guide the child's

behavior and interactions so that they know what is socially acceptable and expected in the particular situation. The use of social stories has been demonstrated to lead to improved behavior and social functioning among children with ASD in schools and the community before new social situations with unfamiliar people (Kokina & Kern, 2010). However, there is a gap in the literature exploring the effects of a social story on children with ASD in preparing them to undergo medical imaging and the best method for delivering them.

Previous researchers have demonstrated that social stories can be delivered on iPads (Kagohara et al., 2013, Moore et al., 2013, Murdock et al., 2013, Vandermeer et al., 2013). Children with ASD enjoy iPads, are familiar with how they work, and are physically able to tap or slide their fingers across the iPad screen (Goodin, 2010). Thus, a social story delivered on the iPad as an approach to preparing a child for a medical procedure may provide the child with an increased perception of control of the situation because they are able to visualize, hear, anticipate, and operate the device.

The purpose of this case study was to compare the anxiety and challenging behaviors between one child with autism who underwent the standard preimaging preparation and another child with autism who was prepared for a medical imaging procedure with a social story intervention, delivered using the iPad application. A secondary purpose was to compare the anxiety of the parent who accompanied the child through the medical imaging procedure.

Case description

Presentation

Two boys with ASD who were scheduled for elective nonemergent CT scans at a tertiary care children's hospital imaging department in the Midwestern United States were selected to be studied in this University, and Hospital Institutional Review Board approved the study. Child 1 was a 16-year-old boy with autism and shunted hydrocephalus, scheduled for a CT scan of his head. Before the CT scan of the head, Child 1 received the social story intervention, delivered using the iPad application. Child 2, who received usual care, was an 8-year-old boy with autism scheduled for a CT head scan of the sinuses. He received preparation with verbal instruction before the CT scan. Both the procedural scans occurred in the imaging department of Children's Hospital of Wisconsin. In both cases, the parent/caregiver accompanied the child to the imaging room.

The two boys were selected for this case study comparison based on their matching characteristics of gender, imaging procedure ordered (CT head scan), and their underlying diagnosis of classic autism. Selecting the same imaging procedure and diagnosis allowed for control of other variables that would impact the outcome measures. For example, procedure time and challenging behaviors that may relate to severity of a child's ASD and the type of procedure would impact the expected length of set up time and total length of the imaging procedure.

Procedure

There were two researchers assigned per child/parent dyad. Data were collected at three time points by two researchers. The first researcher recruited the child with ASD and their parent before the start of the CT scan, in the imaging waiting room of the hospital, via an Institutional Review Board approved flyer. The parent provided informed consent before participating in any data collection. The child

provided assent. Next, the child was randomly assigned to the intervention group (iPad app) or the control group (usual care). The first researcher completed the data collection on the child and the parent before and after the intervention or treatment as usual. The data collection for the child was blood pressure (BP) and heart rate (HR) as a proxy for anxiety, and the data for the parent were the State Anxiety measure of the State-Trait Anxiety Inventory (STAI-S; Spielberger & Gorsuch, 1983). There are 20 items on the STAI-S that capture the state anxiety. These items relate to feelings of apprehension, tension, nervousness, and worry as the experiences that are felt “right now” (Spielberger & Gorsuch, 1983). Each item in the 20-item inventory is rated on a Likert scale of 1–4, with 1 representing “not at all” and 4 “very much so.” Anxiety scores were determined by adding the weighted scores for all 20 items. Scores ranged from 20 (low level of anxiety) to 80 (high level of anxiety). The tool is written at a sixth grade level and takes approximately 5 min to complete.

After the child was called back to the CT scan room, a new (second) researcher who was blinded to intervention group walked back to the imaging room and collected outcome data on behaviors and time to complete the procedure. The first and second researchers did not correspond with each other about the child being in the intervention or usual care group. The child's anxiety was assessed before/after iPad app or usual care, with BP and HR, which is considered a biological proxy for anxiety level. The child's BP and HR were measured before and after the intervention using a battery-operated Omron BP-652 Series automatic wrist cuff (Omron Healthcare Inc, Bannockburn, IL) supplied by the principal investigator (PI) for the study. This type of cuff is viewed as less invasive than the traditional sized BP cuff, with the same reliability of results (Saladini, Benetti, & Palatini, 2010).

Child behavior was measured with the Behavior Observation Tool-ASD Health Care Setting (BOT:HCS) developed by the PI for the study (Figure 1). Items on the tool were established based on two focus groups, which included both parents and HCPs of children with ASD (Johnson, Bekhet, Robinson, & Rodriguez, 2013b). The BOT:HCS is shown to have acceptable internal reliability (0.71) and interrater reliability (0.9; Johnson et al., 2013a). It has three behavior domains: self-injury, activity, and self-stimulatory behavior. A total score is calculated by summing the presence of events (yes = 1 and no = 0) recorded by the observer during the procedure for each of the 27 behaviors. The observer was blinded to knowing whether the child was in the intervention group or the usual care group.

Figure 1. Behavior observation tool: autism spectrum disorders in the health-care setting.

- I. Self-Injury
 1. Chewing own skin
 2. Hits self on head
 3. Hits other body part with hand
 4. Hits head on surface
 5. Hits other body part on surface
 6. Picking own skin
- II. Self-Stimulatory/Self-Calming
 7. Chewing toy /playing with toy
 8. Covering ears with hands
 9. Finger flicking
 10. Hand flapping
 11. Jumping

- 12. Rocking
- 13. Lining things up
- III. Anxiety/Hyperactivity/Injury to Others
 - 14. Biting care -giver
 - 15. Crying/tears
 - 16. Grasping person's face or other body part
 - 17. Hitting other person
 - 18. Kicking other person
 - 19. Laying on floor/throwing self down
 - 20. Moving around room/exploring
 - 21. Picking/chewing equipment/lines
 - 22. Pinching other person
 - 23. Running out of room
 - 24. Spitting other person
 - 25. Staring at parent/caregiver
 - 26. Swearing/cursing
 - 27. Throwing items
 - 28. Yelling

Procedure length was measured at four different intervals from time in the procedure room (T1) to time on the table (T2) to time laying still enough to start the procedure (T3) and time the procedure was complete (T4) for each child. Additional comments by the observer were recorded in a text box. For example, use of a seat belt restraint was recorded in this text box. At the conclusion of the imaging, each parent and child received a \$15 gift card in appreciation of his or her participation.

Results

Both children completed the CT scans. Demographic characteristics of the two individuals are listed in Table 1, and the results for the outcomes of anxiety, challenging behaviors, and time are found in Table 2. For the time outcome, the child exposed to the social story intervention, delivered using the iPad application (Child 1) had a shorter (3 vs. 7 min) time from T2 to T3 (i.e., time on table until time lying still enough to start the CT scan) than the child prepared with usual care (Child 2). In addition, the parent state anxiety decreased more (9 points) in the parent of Child 1 compared with Parent 2's anxiety that decreased by 6 points. Child 1 had no challenging behaviors during the CT scan. Child 2 exhibited two challenging behaviors during the CT scan, which consisted of frequent questions and moving around. Neither child required sedation during the imaging procedure.

Table 1. Demographics of child and parent

Demographics	Child 1	Child 2
Child		
Age	16 years old	8 years old
Diagnosis	Autism with shunted hydrocephalus	Autism
Procedure	CT scan of head	CT scan of sinuses
Parent/caregiver		
Role	Mother	Grandmother

Age	52 years old	61 years old
Race/ethnicity	White non-Hispanic	White non-Hispanic
Marital status	Married	Married
Education	Some college	Postgraduate
Number of siblings	0	6
Number of siblings with autism	0	0
Living arrangements	Part time with mother	Full time with grandmother

CT = computed tomography.

Table 2. Outcomes of time, anxiety, and challenging behaviors

Outcomes	Child 1 (intervention)	Child 2 (usual care)
Time (min)		
Time entering room (T1)	0	0
Time on the table (T2)	1	1
Time laying still enough to start procedure (T3)	3	7
Time procedure complete (T4)	2	2
Overall procedure length	6	10
T3–T2	2	6
Anxiety		
Child BP and HR (pre)	125/86, 92	115/79, 114
Child BP and HR (post)	140/92, 95	117/81, 115
Parent state anxiety (pre), points*	50	29
Parent state anxiety (post), points*	41	23
Child challenging behaviors	0	2 (frequent questions, moving)
Other comments	Child wore seat belt and head strap and held parent's hand.	Child wore seat belt and head strap.

BP = blood pressure; HR = heart rate (beats/minute).

*Range = 20 (low anxiety) to 80 (high anxiety).

Discussion

This case study compared the parent and child anxiety, child challenging behaviors, and procedure length of two children with autism undergoing a CT scan of the head. The feasibility of the iPad app social story intervention was established. The age difference for the boys in this case report is a limitation. Both of parents/caregivers reported that their child had a diagnosis of autism, which is the lowest functioning type of ASD. The previous literature shows that completing imaging without sedation among children with autism is difficult and that parents and children are anxious and the children may have challenging behaviors (Davis et al., 2011, de Andres-Garcia et al., 2013, Lovell et al., 2012, Peacock et al., 2012).

The social story intervention, delivered using the iPad application, appears feasible. Child 1 who received this intervention was attentive to the iPad app social story and was able to manipulate the iPad touch screen and advance the screens. The child completed the story in approximately 5 min

while waiting to be called back to the imaging room. The entire time for consenting, intervention, and measures was approximately 15–20 min and was similar for both children. Furthermore, both children cooperated and completed the CT scan. Thus, the 15 min in preparation time seems manageable in the waiting room.

Results for time and challenging behaviors when comparing Child 1 (intervention) with Child 2 (usual care) showed that there was a shorter time and fewer challenging behaviors for Child 1 compared with Child 2. These findings are consistent with previous research that indicated the efficacy of a social story intervention in other settings (schools and communities) that prepares the child for the steps of a social situation that requires cooperation (Kokina & Kern, 2010). Child 1 seemed to be calm and in a good mood. He did not appear concerned with the imaging procedure. His BP was higher (Table 2) after the intervention than before. It should be noted that according to the STAI-S, his mother's anxiety was also still high (41 points), although it decreased 9 points after the intervention for her son. This finding may mean that the mother's anxiety may influence the child's anxiety (BP and HR), although may have had more anxiety because of his age (16 years old) and having more exposure to health-care experiences. When children with ASD are anxious, they have difficulty with verbal instructions. Literature shows that parents of children with autism tend to be anxious (Lovell et al., 2012, Lovell et al., 2013). The social script intervention before the procedure allowed Child 1 to be prepared for the steps of the CT scan, and he was able to follow the steps as the education was delivered via the iPad format with the expectations for his behavior explained in the social script (Johnson and Rodriguez, 2013, Metzger et al., 2013). Thus, the child can still benefit from the social script preparation for completion of the imaging even with high anxiety before and during the procedure.

In the imaging room, Child 1 appeared to instinctively follow directions. When he was on the table, he appeared to be concentrating to hold very still. After the procedure, the mother reported that she was “shocked” by his cooperation and lack of need for sedation. She stated, “I am so impressed that we did not have to use sedation. This has never happened before. This needs to be in every hospital because it can help so many other children with autism.” Past experiences could play a role in a parent's anxiety. Based on this finding, nurses could address past experiences with parents before the procedure to possibly decrease a parent's anxiety.

While Child 2 was in the imaging room, he moved around and had frequent questions. Both these behaviors required extra time and actions by the HCPs to help him hold still for the examination. His behavior could be related to a lack of understanding of the expectations of the steps of the procedure. Verbal instructions (usual care) can be difficult for children with autism to process in stressful situations (Johnson and Rodriguez, 2013, Johnson et al., 2013a). The additional challenging behaviors exhibited by Child 2 likely contributed to the longer time for the child to complete the procedure.

Conclusion

This case study demonstrated the feasibility and potential efficacy of a social story intervention, delivered using the iPad social script application for preparing a child with ASD for imaging. We compared two children with similar diagnoses of autism undergoing similar procedures (CT scans of the head). Based on the feasibility of the app, we trialed it in a larger study ($n = 32$) where we collected data from a wide variety of imaging procedures for children with ASD aged 4–18 years (in review). The

results from the larger study have the potential to change health-care practices for procedure preparation for children with ASD. The book version of the app called “Here we go to Imaging” is available for free download at maxishare.com. We plan to release the app “Going to Imaging” on the Apple store. Future studies could explore other anxiety-reducing strategies for parents, such as exploring their past experiences with imaging, specific behavior triggers for their child, and a suitable reward that their child for completing the imaging.

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Suggested Reading

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