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Autism and Research Using Magnetic Resonance Imaging

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A B S T R A C T

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This qualitative study explored the experience of participating in a research study using magnetic resonance imaging (MRI) for children with autism spectrum disorder (ASD), typically developing (TYP) children, and their parent. It also assessed the feasibility, efficacy, and acceptability of the *Going to MRI for a Research Study* iPad application (app), developed by the primary author, available for use for MRI preparation. The app provides a description of the steps of the MRI procedure, from the child's perspective, outlining expected behaviors and responses. Ten English-speaking parent/child dyads (n = 20) participated in an audiotaped question guide-facilitated telephone interview about their experience in the MRI study. Participants confirmed the iPad app's feasibility, efficacy, and acceptability. ASD child/parent themes differed from TYP child/parent themes. More children with ASD who used the app completed the MRI than without it. The iPad app may help children with ASD complete MRIs in future studies.

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Introduction

Autism spectrum disorder (ASD) is a pervasive developmental disorder with documented abnormalities in brain structure and function, as compared with typically developing (TYP) counterparts (Volkmar, 2011; Wang et al., 2013). The prevalence of ASD is one in 68 children in the United States for children 8 years old at select surveillance sites (Centers for Disease Control and Prevention [CDC], 2014). Approximately 38% of these children also have intellectual disability (intelligence quotient [IQ] <70; CDC, 2014). Persons with ASD display persistent social communication and social interaction deficits and restricted repetitive patterns of behavior, interests, or activities, and sensory sensitivities (American Psychiatric Association, 2013). Repetitive patterns of behavior may include movements (e.g., hand wringing) and/or vocalizations (e.g., scripted language). In addition, individuals on the spectrum

often present with behavioral rigidities and exhibit challenging behaviors during transitions and/or changes in routine (Johnson & Rodriguez, 2013; CDC, 2014). These behaviors are markedly different from that of their TYP peers (CDC, 2014).

Given the neurologic underpinnings of ASD, research in neuroimaging is of great scientific significance and increasingly incorporated into study designs. Specifically, research studies have used neuroimaging techniques, such as magnetic resonance imaging (MRI) or diffusion tensor imaging, to examine brain structure and function in this population, including task-evoked brain responses (Ismail et al., 2016).

Problems with completing MRI in research studies and hospital settings for children with ASD are well documented. In hospital settings, children undergoing MRIs can experience anxiety, claustrophobia, and fear during the scanning experience and often require sedation (Koller & Goldman, 2012; Munn & Jordan, 2012). Furthermore, the scanning environment presents unique sensory challenges for individuals with ASD (e.g., loud noises and/or the bed shaking). Parents of children with ASD can be anxious about MRI scanning as watching the child in the MRI is stressful for the whole family and may impact the successful completion of the MRI (Simonoff et al., 2008). Although previous research showed that repeated exposure to MRI was associated with lowered anxiety in children with ASD (Chapman, Bernier, & Rusak, 2010), first-time MRI participation remains problematic.

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Interventions to prepare children for MRI vary in approach and effectiveness. In the hospital setting, the strategies reported to be effective in reducing fear, anxiety, and claustrophobia and in reducing the need for sedation in children undergoing MRI include open MRI, practice in a mock MRI, audiovisual systems, cognitive behavioral therapies, guided imagery, and pediatric preparation booklets; all were found to have some positive effect on at least one outcome (Munn & Jordan, 2012). Another approach is to perform the MRI at night as the child is more likely to sleep (Nordahl et al., 2008). Recent research reports on a multistep protocol using principals of applied behavior analysis at a larger research center that facilitated completion of MRI for children with ASD (Nordahl et al., 2016). Although multiple rewards can help TYP children aged 9 to 13 years complete MRIs (Schlund et al., 2011), there is limited literature on effective preparation of children with ASD for the new experience of research study using MRIs to decrease their stress and gain their compliance.

Our previous research found that ill or injured children and their parent had less anxiety (than the control group that received typical care) and challenging behaviors and better compliance with diagnostic imaging when nurses prepared them with an iPad application (app) that used a social script to foreshadow the imaging process and appropriate behavior (Johnson et al., 2014). Social scripts, which can be delivered via an iPad app, are words, pictures, video, and sounds that model acceptable participation in a procedure by referencing other's perspectives and providing the appropriate responses for the person about to undergo a procedure such as MRI (Gray, 2003; Thompson & Johnston, 2013; Vandermeer, Beamish, Milford, & Lang, 2013).

Currently, there is no research on the experience of children and their families on the experience of undergoing a voluntary research study using MRI studying research task-evoked measures. Likewise, there is no standard approach to preparing children with ASD for MRI in research studies.

The study had two aims:

1. To assess the experience of participating in a research study using MRI for a child with ASD or a TYP child and an accompanying parent.
2. To evaluate the feasibility, efficacy, and acceptability of the *Going to MRI for a Research Study* iPad app consisting of research task, mock MRI scanner, MRI photographs, and audiorecording of the sound of the MRI scanner.

The *Going to MRI for a Research Study* iPad app

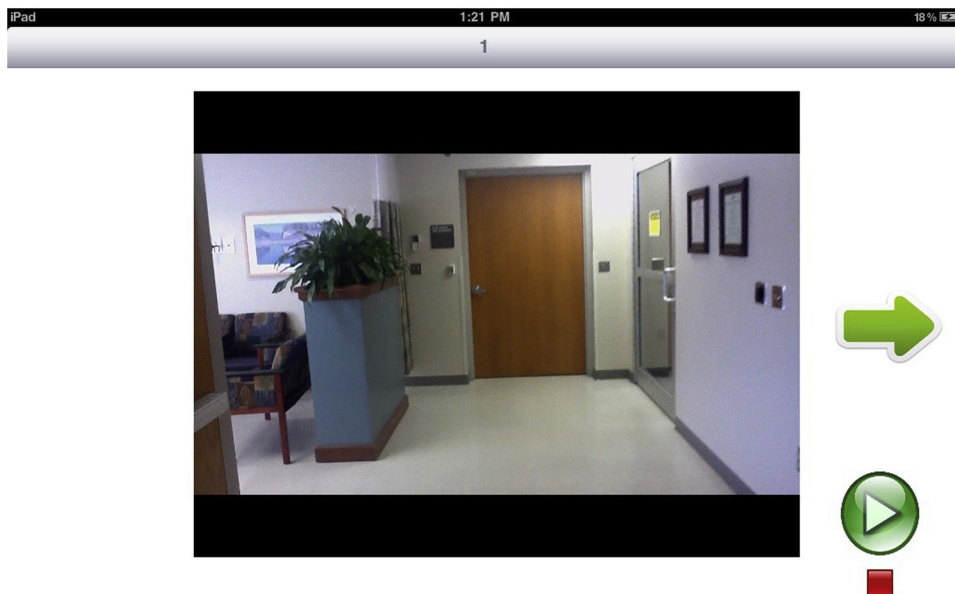
The *Going to MRI for a Research Study* iPad app, developed by the researchers, is a social script to prepare the child for the MRI. It is a story with a series of photographs of the research task, mock MRI scanner, real MRI scanner, and audiorecording of the sound of the MRI. The buttons on the app allow the user to hear the text read aloud or not and allows the user to move backward and forward through the app at their own pace. Four representative screenshots of the app are presented herewith:

1. This photograph, on the opening screen of the app, foreshadows the child and parent's arrival at the MRI scanner to meet the researcher.
2. This is a photograph of the mock scanner and accompanying text.
3. This is a photograph of a participant in the MRI scanner and accompanying text.
4. This is the final screenshot intended to decrease anxiety and motivate participation.

Methods

Design

This study is part of a larger study on neural correlates of goal-directed behavior (Salowitz et al., 2014). The larger study had a



**I am taking part in a research study. My parent will be with me.
The first part of the study is just practice. I will go to the
building and meet the researchers at the front door.**

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