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Using social narratives to improve the healthcare experiences of children diagnosed with autism spectrum disorder

Margaret Spindel
James Madison University

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Using Social Narratives to Improve the Healthcare Experiences of Children Diagnosed with

Autism Spectrum Disorder

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An Honors College Project Presented to

the Faculty of the Undergraduate

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by Margaret Spindel

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Accepted by the faculty of the College of Health and Behavioral Sciences, James Madison University, in partial fulfillment of the requirements for the Honors College.

FACULTY COMMITTEE: HONORS COLLEGE APPROVAL:

Project Advisor: Julie Strunk, Ph.D., R.N.   Bradley R. Newcomer, Ph.D.,
Associate Professor, School of Nursing   Dean, Honors College

Reader: Betsy Herron, Ph.D., R.N., C.N.E.
Assistant Professor, School of Nursing

Reader: Katherine Robinson, M.T., BCBA, LBA
Instructor, College of Education

PUBLIC PRESENTATION

This work is accepted for presentation, in part or in full, at James Madison University on December 14th, 2017.

Dedication

I would like to dedicate this senior honors project to my parents, Dr. Jonathan and Nancy Spindel. From supporting me in so many more ways than one, nothing would make me happier than to become you both when I grow up. You have never given up on me, and more importantly never let me give up on myself.

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Abstract

Children with Autism Spectrum Disorder (ASD) often experience significant emotional stress when they visit a healthcare provider. The focus of this research project was to explore the use of social narratives to help reduce stress associated with this environment. Social narratives are short stories designed to walk a child through a potential situation that they will encounter, that they may not be familiar with, or that they are not currently handling properly. As part of an initial literature review, evidence for the need for additional intervention in the healthcare setting for children with ASD was established. Continuing literature review then focused on the use of social narratives in children with ASD, establishing a set of best practices for using social narratives within that population. These studies showed promise that the social narratives could be an effective intervention to reduce stress in these environments. Results from this literature review helped to point out the need for further narrative development specific to children with ASD, establish the validity of the practice, and determine additional controls and variables required to develop an effective set of social narratives for this population for use in medical settings. In the next phase of this work, further research will be conducted using a new set of social narratives for children with ASD to establish what factors need to be present to maximize the effectiveness of reducing stress and anxiety related to transitions and unfamiliarity in the healthcare setting with this intervention.

Using Social Narratives to Improve the Healthcare Experiences of Children Diagnosed with

Autism Spectrum Disorder

Literature Search

A literature search was conducted using the Cumulative Index to Nursing and Allied

Health Literature (CINAHL). The key words used when searching were "social narrative",

"social stories", "validity", "Autism Spectrum Disorder", and "healthcare". As defined by the

research team, inclusion factors for this review were articles that had been published in 2012 or

later, had been peer reviewed, written in English, and demonstrated a clear method of data

collection and analysis. Exclusion factors for this review included articles with discussion and

opinions not representing original research, and studies that focused on social narratives in

individuals other than children diagnosed with ASD.

Autism Background

Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant

social, communication, and behavioral challenges. A diagnosis of ASD now includes several

conditions that used to be diagnosed separately: autistic disorder, pervasive developmental

disorder not otherwise specified (PDD-NOS), and Asperger syndrome. According to the most

recent Center for Disease Control and Prevention data, 1 in 68 children is diagnosed with ASD, it

is about 4.5 times more prevalent in boys than in girls, and occurs equally across all racial and

socioeconomic classes (Centers for Disease Control and Prevention, 2017a). As a diagnosis,

ASD is increasing in prevalence rapidly worldwide since it was first discovered in the 1940s.

The increase in diagnosing of ASD could be due to several different reasons, including the

expanding of the diagnostic criteria, increased awareness of ASD, changing the way ASD is

studied, or a true increase in the prevalence of the disability (Neurodevelopmental Disorders, 2013). While there have been many different theories as to the origin of ASD, there remains no definitive, accepted clinical explanation for its cause.

To be diagnosed with ASD, children must meet a strict set of criteria as laid out in the Diagnostic and Statistical Manual of Mental Disorders (DSM–5). The key traits seen in these young people are persistent impairments in reciprocal social communication and social interactions, as well as restricted repetitive patterns of behavior, interests, and activities (Neurodevelopmental disorders, 2013). The aforementioned deficits must have been present from early childhood and put severe limitations or impairments on the individual's everyday functioning (Neurodevelopmental disorders, 2013). Additionally, the social communication impairments should be misaligned with the developmental level of the individual; impairments are greater than what would be expected for the child's developmental level (Neurodevelopmental disorders, 2013).

Barriers to Healthcare for Children with ASD

Between the different diagnostic criteria involved in ASD, tackling an everyday task like going to a doctor's appointment can become much more complex. Not only do families suffer from an increase of anxiety just by taking a child to the clinic, but the child suffers from anxiety as well by experiencing things that are out of his or her comfort zone. Something as simple as "take off your shoes and step on the scale" can lead to a meltdown because the child with ASD is anxious concerning what this situation will lead to and it is out of his or her ritual and routine. The major barriers to the healthcare experience can be broken down into three major categories; stressors felt by the child, stressors felt by the parents and family, and stressors felt by members of the healthcare staff.

Children with ASD experience a significant amount of emotional stress when they visit a healthcare provider due to a variety of reasons. One primary feature of ASD is the persistent impairment of reciprocal social communication and social interaction (Neurodevelopmental disorders, 2013). This means that these children have trouble interacting with their providers and verbalizing how they are feeling. When children have trouble expressing their feelings, they may have issues getting across the characteristics of their pain, as well as the relieving or aggravating factors (Bultas, McMillin, & Zand, 2016; Muskat et al., 2015). With the lack of communication, many other injurious behaviors can commence including leaving the healthcare setting with unmet needs (Ahmedani & Hock, 2012; Bultas, 2012; Bultas, McMillin, & Zand, 2016; Johnson et al., 2014) and engaging in behaviors that could potentially cause further harm (Johnson et al., 2014; Johnson, Lashley, Stonek, & Bonjour, 2012). A study, conducted by Johnson and colleagues discussed taking a child with ASD to an imaging appointment where the child was held down to receive a clean image (Johnson et al., 2014). This practice was regularly executed in the clinic showing creating an environment of fear and anxiety among those children with ASD (Johnson et al., 2014). Additionally increasing anxiety, a hospital or other healthcare environment, sees frequent changes that are unfamiliar and can create a troublesome environment for the child with ASD (Muskat et al., 2015). Some parents state that transitions can be especially difficult for their child with ASD and that their deficits can be exacerbated and cause an anxiety increase with the new environment (Johnson, Lashley, Stonek, & Bonjour, 2012; Muskat et al., 2015).

When an individual displays fear and anxiety in a healthcare setting, it can greatly affect the client's trust towards the healthcare provider, as well as creating negative behaviors resulting in their fear and mistrust. This can lead to healthcare concerns that are not addressed and

problems that may not be resolved. This is one factor that contributes to children with ASD receiving significantly lower healthcare quality than their typically developing peers (Ahmedani & Hock, 2012; Bultas, 2012; Zuckerman, Lindly, Bethell, & Kuhlthau, 2014). Children suffering from a comorbid psychiatric disorder along with their ASD also had significantly poorer health outcomes compared to typically developing children, which is significant because 66.2% of children with ASD have a comorbid psychiatric disorder and 61.8% of those have more than one comorbid psychiatric disorder (Ahmedani & Hock, 2012).

Parents and other family members also suffer from a significant number of stressors involved in taking their child with ASD to a healthcare appointment. Many parents experience increased anxiety and feel overwhelmed by the visit (Bultas, McMillin, & Zand, 2016). This stress can cause parents to cancel appointments, exaggerating their anxiety due to a delay in seeking treatment for problems that their child is experiencing (Johnson, Lashley, Stonek, & Bonjour, 2012). When mothers were interviewed in a study analyzing the barriers felt when taking their child with ASD to an appointment, many stated that they "felt stress and anxiety over their need to 'drive' the healthcare visit by repeating child specific instructions and information on every visit" (Bultas, 2012, p. 465). They also felt that, in general, healthcare providers did not understand what it was like to work with a child with ASD, causing them greater stress as they needed to be increasingly watchful of their child around individuals untrained and unaware of how to handle their child's behavior (Bultas, McMillin, & Zand, 2016, Bultas, 2012). The impact of a child with ASD in a healthcare environment affects not only family dynamics but finances as well. Parents reported that they spent over one thousand dollars out of pocket on medical expenses for their child with ASD as well as experienced employment

difficulties due to their extended family requirements. (Zuckerman, Lindly, Bethell, &

Kuhlthau, 2014).

Lastly, the healthcare staff struggle when they are given a patient for whom they are not

equipped to handle his or her behavior. On a physiological level, children with ASD respond

very differently to therapies typically prescribed, meaning that healthcare providers may not be

able to prescribe their typical treatments and may not be fully prepared to treat the child (Bultas,

2012). Along with this comes provider frustration, stemming from a lack of understanding as to

why the child is acting out in a manner unlike typically developing children and without the

knowledge or tools to assist in calming the child (Vaz, 2013; Bultas, McMillin, & Zand, 2016;

Bultas, 2012). Anxiety can also be seen among staff members when they are overwhelmed and

do not know how to handle a specific behavior (Johnson, Lashley, Stonek, & Bonjour, 2012).

When the child begins to respond in a dangerous or unusual way, staff members can be put in

danger especially without the tools to calm them down properly and ethically (Johnson, Lashley,

Stonek, & Bonjour, 2012).

While every child with ASD struggles with different things in a healthcare setting, the

greatest overarching theme is that they receive a lower quality of healthcare than typically

developing children (Ahmedani & Hock, 2012; Bultas, 2012; Zuckerman, Lindly, Bethell, &

Kuhlthau, 2014). This decreased quality is manifested in poorer patient outcomes and a higher

risk of injury for both the patients and staff (Johnson et al., 2014; Johnson, Lashley, Stonek, &

Bonjour, 2012). Within the poorer outcomes, often the frustration of the visit leads to

prematurely leaving the site, forcing patients and caregivers to leave with their needs unmet

(Ahmedani & Hock, 2012; Bultas, 2012; Bultas, McMillin, & Zand, 2016; Johnson et al., 2014).

Parents described feeling like healthcare providers put their child's care in a strictly outlined box

and if the child's profile didn't fit the predetermined profile their needs were neglected (Bultas, 2012). With neglected needs, an array of problems reveal themselves, including increased caregiver anxiety and strain (Bultas, 2012). It is clear that there is a gap in healthcare for children diagnosed with ASD that requires intervention and education to inform healthcare providers who interact with these children.

Social Narratives Introduction

Social narratives, also known as social stories, were first introduced by Carol Gray in the early 1990s. The stories are literally accurate short narratives intended to walk a child through a potential situation that they may encounter with which they may not be familiar, or that they are not currently handling properly (Gray, n.d.-c). The narratives are designed to introduce and support socially appropriate behaviors and provide the children with the tools necessary to navigate these scenarios so that they are not caught off guard (Gray, n.d.-c; Otero, Schatz, Merrill, & Bellini, 2015). The stories may include pictures depending on the child's level of functioning. (Iskander & Rosales, 2013). Gray (n.d.-c) refers to the writers of these stories as "Authors" to highlight that the writers are creating this content with their audience in mind, ensuring that the structure of the stories are favorable to the children with ASD and those working with them.

Social Stories, as constructed and defined by Gray, follow ten specific criteria for classification as an official "Social Story" (Gray, n.d.-c). When a social narrative is classified as a social story without capitalization, it means that at one point the story fit the criteria, however the criteria has changed and the social story is not currently classified as an official Social Story. The capitalization is an indicator that the story is currently up to date on all requirements as set forth by Carol Gray (Gray, n.d.-b). In this literature review and call for further research, the term

social narrative is used as the construction of future narratives and review of past studies does

not strictly adhere to Gray's guidelines. Social narratives is the generic name for any work

created by an educator, parent, or other professional to guide specific behavior for children with

ASD (Lofland, 2015). They provide a useful tool for the children who do not follow social norms

typically and need guidance when confronted with a new or different circumstance (Lofland,

2015).

When asked about the history of Social Stories, Gray claims that she cannot separate her

own history from those of the stories themselves (Gray, n.d.-b). When writing her first social

story in 1990, Gray observed a child in a gym class who was not understanding the rules to a

game. She decided to write out how to play the game from the child's perspective so that he

could understand what was expected of him (Gray, n.d.-a). While the story she constructed no

longer fits the current Social Story requirements, it began her search for further research and

development of this tool for children with ASD to use. Gray writes that the development of

Social Stories has been an evolving process, changing slowly to increase success with each new

generation of regulations and stories (Gray, n.d.-a).

When implementing social narratives, technology has been shown to be an appropriate

method to convey educational and communicative tools to children with ASD (Fletcher-Watson,

Pain, Hammond, Humphry, & McConachie, 2016). Using an easily accessible technological

device, social narratives are read to the child or by the child before entering the new situation as

shown by the narrative (Otero, Schatz, Merrill, & Bellini, 2015). Studies have shown that this

intervention can have its highest efficacy rates with children who have a higher cognitive

functioning level (Hutchins & Prelock, 2013). Considering different ability levels and

personalizing the story and design to each child could enable this tool to work more prominently

for an audience with variable ability levels. (Hutchins & Prelock, 2013; Johnson, Bekhet,

Robinson, & Rodriguez, 2014; Kopecky, Broder-Fingert, Iannuzzi, & Connors, 2013; Thompson

& Tielsch-Goddard, 2014).

Social Narrative Validity

In analyzing the validity of social narratives, there is considerable variability throughout

the studies (Hutchins & Prelock, 2013; Sani-Bozkurt & Vuran, 2014; Vandermeer, Beamish,

Milford, & Lang, 2015). Every child with ASD has slightly different skills and traits that cause

their functionality with ASD to place them on a different place on the spectrum (Bultas, 2012).

Using a tool like social narratives, children with certain skills may respond more positively than

others. Social narratives have a growing popularity among the special education population due

to their availability and ease of implementation. They get a considerable amount of attention

even though the effects have been classified in some studies as "low to questionable" (Otero,

Schatz, Merrill, & Bellini, 2015). Among several different studies showing both positive and

negative trends for the use of social narratives, the conclusion was that there is a need for further

research (Johnson et al., 2014; Sani-Bozkurt & Vuran, 2014; Vandermeer, Beamish, Milford, &

Lang, 2015). When looking at each of the studies, for some of the children social narratives

worked consistently at reducing target behaviors. For other children, the social narratives did not

affect their behavior (Otero, Schatz, Merrill, & Bellini, 2015). The polarizing results raises the

question of what the difference is between the cases that worked using social narratives versus

those that were ineffective.

In many studies, researchers found that social narratives had a largely positive affect on

their samples (Hutchins & Prelock, 2013; Iskander & Rosales, 2013; Johnson & Bree, 2014;

Pane, Sidener, Vladescu, & Nirgudkar, 2015). They reported a decrease in target behavior and

reported back that there was strong evidence that social narratives were an effective tool to teach social skills to children with ASD. In one study, multiple behaviors were targeted and the results concluded that members of the study showed decreased levels for at least one target behavior (Iskander & Rosales, 2013). In an additional study, it was shown there was a positive response to social narratives for two participants and the response did not decrease when the intervention was removed (Pane, Sidener, Vladescu, & Nirgudkar, 2015). Without a decrease after use provides evidence that social narratives do not require a slow removal or fading protocol to maximize efficacy.

Although many studies report positive findings, there are several other studies that indicate the need for further research to determine the validity of this intervention. A meta-analysis of social story efficacy found the outcome of children who have used social narratives is questionable and variable but shows considerable promise, stating that further research with experimental controls should be conducted to determine if the tool can be considered as evidence-based practice (Sani-Bozkurt & Vuran, 2014). Another study showed a need for the sources of variability to be studied as the narratives were effective for some children in certain scenarios but ineffective for others (Vandermeer, Beamish, Milford, & Lang, 2015). Looking at the use of a social narrative in assisting a child going to an unfamiliar healthcare procedure, researchers found there was a need to look further into parental preparation when using the social narratives (Johnson et al., 2014). In conclusion, social narratives, although showing strong promise in the ASD world, may not be considered evidence-based practice until further research. There is a considerable need for new research with various controls and variables to determine what specifically makes social narratives effective and what characteristics the audience needs for the intervention to be successful.

iPad Validity

The validity of using iPads for therapeutic use in children with ASD has been discussed and proven by many different research studies (Fletcher-Watson, Pain, Hammond, Humphry, & McConachie, 2016; Kagohara et al., 2013; King, Thonrieczek, Voreis, & Scott, 2014; Vandermeer, Beamish, Milford, & Lang, 2015). The accessibility of the touchscreen and technology proved favorable when asking families and children with ASD if they would be willing to incorporate the iPad into their everyday lives (Fletcher-Watson, Pain, Hammond, Humphry, & McConachiee, 2016). Additionally, it has been shown that all youth, but specifically those with ASD, enjoyed using technology in their daily lives (Otero, Schatz, Merrill, & Bellini, 2015). Children who are inclined to use the technology to help with their therapies learned more readily as they were enjoying what they were doing.

When a child was given technology with little instruction, it was likely that they were not able to use the tool as effectively or properly as they would have, if they we had been guided by a professional. King, Thonrieckzek, Voreis, and Scott (2014) revealed that when given iPads with applications for various therapeutic and educational uses, children used the iPad in its intended function 69% of the time and used the iPad inappropriately 31% of the time. When this study was concluded, it found the evidence was favorable to iPad use in the classroom setting and that it would most likely be an appropriate supportive device to those with ASD (King, Thonrieczek, Voreis, & Scott, 2014).

Parents found that using iPads was convenient as there are limited technological faults and they had a positive effect on the life of the family with a child with ASD (Fletcher-Watson, Pain, Hammond, Humphry, & McConachie, 2016). Because of the simplicity of the iPad design, it was shown that people with severe learning impairments, as seen in many children with ASD,

can be taught how to operate iPods, iPads, and other similar devices (Kagohara et al., 2013).

These devices could be seen as viable technological aids and can be used to enhance child

development in many ways including academic enhancement, communication skills, relaxation,

and employment and transitioning skills (Kagohara et al., 2013). When iPads are used for

therapeutic reasons, the content of the application is just as important as the device itself.

Applications should abide by best practices as evidenced by research to ensure the best possible

and most effective outcome.

Best Practices for Social Narrative Construction and Implementation

Implementing social narratives leaves a wide spectrum of possibilities in design and

implementation. Variables in the design of the application used to present the social narrative,

the individual structure of the narrative itself, the source of where to get the information to

customize the narrative for each individual child, and the implementation of the intervention can

each be manipulated to achieve the highest rates of success. Through a review of the literature,

several opinions on the best design and implementation strategies to maximize the effectiveness

of the narrative were found.

There is considerable data focused on the development of an iPad application for use

among children with ASD. One premise was that proper use would not be ensured if the device

was simply given to a child hoping that they would get the educational benefits for which the

device was intended (More & Travers, 2013). The applications downloaded onto a piece of

technology like an iPad required continuous monitoring by early childhood professionals to

ensure they are meeting the minimum required guidelines to be effective in the use with children

with ASD (More & Travers, 2013).

In a study published in the International Journal of Child-Computer Interaction, the best practices for designing an iPad application for young children with ASD were determined after studying 41 preschool-aged children with ASD using the applications for 2 months (Fletcher-Watson, Pain, Hammond, Humphry, & McConachie, 2016). The five categories for suggested guiding principles resulting from this study were theoretical foundation, interdisciplinary working, informed design, formative evaluation, and personalization (Fletcher-Watson, Pain, Hammond, Humphry, & McConachie, 2016). When these five best practice techniques were incorporated into an application designed for practicing social communication skills, the application was effective in keeping the interest of the child, which led to getting the most out of the tool. The five principles were recommended for people less familiar with ASD who had a goal of designing an application for this unique population (Fletcher-Watson, Pain, Hammond, Humphry, & McConachie, 2016).

In the physical design of the narrative, small changes can have a big impact when working with the ASD population. In one study of interactive social narratives, a mother pointed out that the word "angry" should be used over the word "upset" because the child did not understand what was meant when the word was not as literal (Sani-Bozkurt, Vuran, & Akbulut, 2017). In the same study, a parent commented on the favorable use of pastel colors over brighter ones as well as the removal of a certain noise when correctly answering questions (Sani-Bozkurt, Vuran, & Akbulut, 2017). A common behavior with children with ASD can be an unusual response to the way things look or sound, therefore limiting the bright colors and loud noises assist in limiting the sensory overload that many children with ASD experience (Centers for Disease Control and Prevention, 2017b). They also suggested that having the interactive narratives be linked closely to realistic situations would increase the ability for the children to

comprehend when to use the social skills that they were being taught (Sani-Bozkurt, Vuran, & Akbulut, 2017). In a separate study using picture schedules in a doctor's office for children with ASD, parents and healthcare providers concluded that breaking up the schedule into smaller sections of the day would overwhelm patients less (Thompson & Tielsch-Goddard, 2014). This same concept can be applied to social narratives. By having the social narratives cover short time periods of an unfamiliar procedure, the overwhelming nature of seeing something new could be decreased.

When designing the narrative, a key feature was personalization to each individual child and their needs. This can be done by using the child's individualized education plan (King, Thonrieczek, Voreis, & Scott, 2014), and consulting parents or other professionals about the child's behavior and needs (Thompson & Tielsch-Goddard, 2014), or having parents review the finalized narratives before the intervention was implemented to be sure the target behavior was correctly identified in the narrative (Hutchins & Prelock, 2013). A concept to avoid when designing social narratives was the "one-size-cures-all" approach (Johnson, Bekhet, Robinson, & Rodriguez, 2014). Individualization of the intervention is crucial to increase the chances of it being effective (King, Thonrieczek, Voreis, & Scott, 2014; Kopecky, Broder-Fingert, Iannuzzi, & Connors, 2013; Thompson & Tielsch-Goddard, 2014). Another step to increase the chance of efficacy was writing the narrative. A brief functional analysis should be done and incorporated into the writing, making the narrative more effective. In a study comparing a narrative with functional analysis to a narrative written without functional analysis, participants effectively decreased their problem behavior as well as selected the functional analysis narrative when asked to choose which narrative technique they preferred (Pane, Sidener, Vladescu, & Nirgudkar, 2015).

The implementation process is crucial in determining how well the child would respond to the narrative intervention. An integral part of implementation that showed positive effects occurred when the child read the narrative themselves, rather than having a parent or other professional read the narrative to them (Otero, Schatz, Merrill, & Bellini, 2015). Assuming the child could read and comprehend the social narrative without considerable guidance, the independence provided the child with a sense of control over his or her environment; a positive factor when working with children with ASD (Johnson & Bree, 2014).

A common theme across many studies was the idea that using repetition could increase the effectiveness of the narrative (Muskat et al., 2015; Hutchins & Prelock, 2013). Repeatedly looking at symbols and narratives assisted the child in retaining more information (Vaz, 2013). Lastly, a combination of social narratives with verbal cues seemed to be more effective than social narratives alone (Sani-Bozkurt & Vuran, 2014). Considering the data for social narrative validity alone can be seen as questionable, when combined with other interventions, specifically verbal cues, the rate of effectiveness was found to be statistically significant. This implies that the combination may be the way in which social narratives could be considered as evidence-based practice (Sani-Bozkurt & Vuran, 2014).

To summarize, the design and implementation factors that go into social narrative testing has many different variables that can be manipulated to formulate the best possible success rate. When using a combination of these best practices for application and narrative development, the validity of the social narrative would strengthen thereby allowing its use to become evidence-based practice. Once evidence-based, the research may expand, allowing increased access to narratives for children with ASD.

Evidence for the use of Social Narratives in Healthcare Settings

Several themes were prominent in the literature when looking at evidence supporting the need for social narratives in a healthcare setting, including benefits of advanced preparation for children with ASD (Johnson, Bekhet, Robinson, & Rodriguez, 2014; Kopecky, Broder-Fingert, Iannuzzi, & Connors, 2013; Muskat et al., 2015) and studies that have previously attempted using social narratives in the health care setting (Johnson & Bree, 2014; Johnson et al., 2014). While the validity of social narratives is variable, for some children with ASD this intervention is completely effective and eliminates many unwanted social behaviors. It is non-invasive and easy to administer, and lets the child be in control of their environment which is something that many children with ASD prefer (Johnson & Bree, 2014).

In a small-scale study, a social narrative was used for children going into imaging. The study was done using just two boys, one given the intervention and one without. The child given the intervention reported no challenging behaviors during the scan as well as having to spend less time in the imaging room altogether (Johnson & Bree, 2014). His mother 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" (Johnson & Bree, 2014, p. 125). The child who did not received the intervention reported two challenging behaviors. This same study was repeated using the same social narrative and conducted on a larger scale. The findings for this report, however showed that the social narrative was effective on approximately half of the participants, a figure that is consistent with the overall theme of studies conducted to learn about the efficacy of social narratives (Sani-Bozkurt & Vuran, 2014; Johnson et al., 2014). Overall, the children who were given the intervention had lowered measured anxiety levels. (Johnson et al., 2014).

When asked in a survey about things that parents do to help prepare their children for the unfamiliar healthcare environment, one mother specifically brought up using social narratives to provide advanced preparation. A statement by the mother shows that many families already use social narratives on their own in an attempt to prepare for unfamiliar healthcare environments:

> So one of the strategies that we use, which I think is probably very common around the table, is a lot of social stories and working very intentionally with our son in advance of the doctor's visits to prepare him for what's going to happen so that he knows, there's going to be five doctors and there may be waits, and so on and so forth (Johnson, Bekhet, Robinson, & Rodriguez, 2014, p. 389).

It also further enforces the belief that advanced preparation would be successful for children with ASD. Advanced preparation is a common comment from parents in healthcare surveys on what they believe would make an appointment for their child go more smoothly (Johnson, Bekhet, Robinson, & Rodriguez, 2014; Kopecky, Broder-Fingert, Iannuzzi, & Connors, 2013; Muskat et al., 2015).

Other suggestions parents reported as helpful for their children with ASD in the healthcare setting is that effective communication can be crucial in developing the relationship between the patient and the provider (Bultas, McMillin, & Zand, 2016; Chebuhar, McCarthy, Bosch, & Baker, 2013; Kopecky, Broder-Fingert, Iannuzzi, & Connors, 2013). Ensuring proper and effective communication can assist in helping the child understand what is expected of him or her which can often be a source of anxiety for the children (Chebuhar, McCarthy, Bosch, & Baker, 2013). Social narratives spell out exactly what is expected of the child throughout the visit as well as aid in appropriate ways of communication.

Conclusion and Future Research

As evidenced by the literature, the validity of using social narratives as a tool with children with ASD is not yet supported as evidence-based practice due to the questionable and variable results from many research studies. When broken down, however, the questionable data shows a clear split between certain children who respond positively to the intervention and those who do not respond at all to the intervention. This indicates that while social narratives can be ineffective in some children, they can be a valuable tool for certain children who are able to use them effectively.

In the medical field, there are significant gaps in the quality of healthcare that children with ASD receive compared to those who are typically developing. Within each of those areas, there is evidence that the involvement of an office-based social narrative program could begin to bridge the gaps to provide increased safety and quality of care. Using the best practices outlined in this literature review, further research needs to be conducted by developing an iPad application illustrating social narratives specific for use in the healthcare office-based setting. As a starting point example, draft story line for this type of social narrative is in the Appendix. While the validity is variable for using social narratives, for some children this intervention could have a positive effect on their day-to-day interactions. ASD is a "spectrum" and there are a wide variety of abilities, both physical and psychosocial (Bultas, 2012). Given this, further research needs to be conducted to examine what skills and traits need to be present in children with ASD to enable them to be successful in their use of social narratives. Results from this study, could lead to data that supports which traits make the use of social narratives beneficial to a child with ASD, specifically in a healthcare setting.

Appendix: Example Social Narrative

I am going to the doctor's office today.

They are going to give me a checkup so that I can go to school.

The first thing I will do is check in at the front desk.

At the desk, the person will
ask me my name.

I will tell them my name.

They will tell me to sit down and
wait for my name to be called.

I will go sit in a chair and wait
until I hear my name.

While I wait, there might be toys
that I want to play with.

I can ask my parent,
"Can I play with the toys?"

If my parent says yes, I may play with the toys
until my name is called.

If my mom or dad says no, I will wait in my chair
until my name is called.

A nurse will come into the waiting room and say
my name.

I will get up with my parent and
we will walk to the nurse.

The nurse will take us to our
next place.

On the way to the room,
the nurse may stop at a scale.

They will ask me to take off my shoes and step
onto the scale.

I will remove my shoes and stand on the scale
until they say I am finished.

Next, I will then step off of the scale and put my
shoes back on.

We will then walk to the room.

I will sit on the table with paper on it.

The nurse may ask me to lie down on my back.

While I lie on my back, I can look
at the pictures on the walls and the ceiling.

The nurse will then look at my head, arms, legs, belly, and back.

My nurse will ask
me many questions.

I can answer them if I know them.
If I do not know the answer, I can
ask my parent to answer for me.

Once the nurse is finished,
they will leave.

My parent and I will wait
until the doctor comes in.

The doctor will come in
and ask me questions.

I can answer them if I know them.

If I do not know the answer, I can ask my parent
to answer for me.

After the doctor is finished,
it is time to go.

I will get down from the table.

Sometimes I may get offered a sticker or another prize.

I did a great job at the doctor's office today!

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