PROVIDERS’ PERCEPTIONS OF A SAFETY-RELATED EDUCATION LEAFLET FOR PEDIATRIC AUTISM SPECTRUM DISORDER

by
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A DNP project submitted to the
School of Nursing
State University of New York
in partial fulfillment of the requirements for the degree of Doctor of Nursing Practice

May 2019
DNP Project Approval Form

This is to certify that Jessica Clark

(Name of Student)
successfully defended their DNP research project entitled:

Providers' Perceptions of a Safety-Related Education Leaflet for Pediatric Autism Spectrum Disorder

on April 29, 2019

(Date)

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Committee Member 1*

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(Signature)

Committee Member 2*

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(Signature)

Committee Member 3*

(Typed Name)

(Signature)

*If applicable
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Acknowledgements

I’d like to express my thanks to my University faculty mentors for their continued support and encouragement: Dr. Nancy Campbell, my committee chair; Dr. Patricia Nisbet; and Dr. Christopher Barrick. I also offer my sincere appreciation to Hannah Lapides for her inspiration, and guidance in implementing my project. Finally, the completion of this project could not have been accomplished without the unwavering love and support of my family. A heartfelt thank you to my son, Knox, who has given me endless inspiration to persevere and better myself, and to my grandfather Richard Dygulski, who provided Knox with unconditional love and care while I completed my work.
Abstract

Background and Significance

Deaths by injury in individuals with Autism Spectrum Disorder (ASD) are significantly higher than other children. Healthcare providers should be educating caregivers on specific safety related to this population. However, resources for this type of education are scarce.

Purpose and Objective

To create a unique, safety education leaflet and investigate its level of usefulness compared to providers’ current educational materials.

Theoretical framework

Pender’s health promotion model focuses on taking measures to promote good health. As Pender intended, the theory guides the provider through teaching safety promoting behaviors, which increases health and safety outcomes for children.

Methods

A safety leaflet was developed and distributed to physicians and nurse practitioners (n=19) at a primary pediatric practice that cares for children (ages 2-15) with ASD. A survey using a 4-point Likert-type scale ranging from 1 (not at all useful) to 4 (very useful) was developed and administered to determine the providers’ level of perceived usefulness of the leaflet.

Results

The majority of providers rated the leaflet as “very useful” or “useful” (n = 10, 83.3%), as compared to and their current education materials, which were “slightly useful” or “not useful at all” (n = 10, 77%). Providers who have been practicing over 20 years (p = 0.036, were especially positive.

Conclusion
The leaflet was perceived as useful, and could help providers educate parents/caregivers of pediatric patients with ASD by facilitating understanding of the unique safety risks within this population, as well as help to understand measures to mitigate injury.

*Keywords: Autism; safety; education; leaflet; providers; perception*
Increased mortality rates have been reported in individuals with Autism Spectrum Disorder (ASD), with research suggesting that the risk of premature death is one to ten times higher in the ASD population than the general population (Pickett, Xiu, Dawson & Lajonchere, 2011). Guan and Li (2017) found that deaths by means of unintentional injury in individuals with ASD were nearly three times as likely as were deaths in the general population, and this excess risk of injury is particularly higher for children. A number of risk factors associated with ASD occur at higher rates in children, which results in these higher injury rates. Such factors include male predominance; child psychological and behavioral problems, including hyperactivity, anxiety, aggressive behavior, cognitive delays affecting mental processing or causal reasoning, and sensory deficits (DiGuiseppi, 2017). Parents and caregivers of children/adolescents with ASD often feel overwhelmed, and have a difficult time seeking answers for their child’s challenging, unusual, and often unsafe behaviors (Bonis & Sawin, 2016). Studies suggest that adequate, clear, and accessible information for caregivers improves health and outcomes, with educated patients being the safest patients (Grissinger, 2009; Kasting, Lake, Vadaparampil, 2017). This project seeks to determine how pediatric healthcare providers perceive a new, concise education leaflet related to safety risks in children/adolescents (ages 2-15) with ASD.

**Background and Significance**

Considering the significant increase in safety risks associated with children/adolescents with ASD, health care providers have a duty to educate caregivers on these risks, and teach how to best manage and mitigate them in order to achieve best health outcomes (Paterick, Patel, Tajik & Chandrasekaran, 2017). Organizations on the forefront of ASD education provide education materials which can be downloaded, printed, or even mailed to the caregiver. However, there are very few resources which contain all-inclusive teaching for the wide-spectrum of safety risks
within the population. The few resources that are all-inclusive, may not be easily-accessed by all, and may be viewed as overwhelming, since they are typically over 60-100 pages in length. Also, despite the education resources being available on the internet, patients and caregivers continue to ask for more written information from healthcare providers (Sustersic, Gauchet, Foote & Bosson, 2016).

Since there are no mainstream, concise education leaflets on safety risks associated with childhood/adolescent ASD, some providers have suggested the need for more concise printed tools to distribute to reinforce teaching that was covered during the appointment (Sustersic, Gauchet, Foote & Bosson, 2016). Previous studies indicate that the impact on knowledge is improved when the leaflets are concise, precise, short, and can be easily accessed by the caregiver for continuous reinforcement (Garner, Ning & Francis, 2012).

**Purpose and Objectives**

Teaching conducted by healthcare providers is critical to reducing injuries and deaths associated with ASD associated safety risks. However, little is known about providers’ current use of or preference for education materials regarding the safety risks of children/adolescents with ASD. This project expanded upon a current gap in resources by developing and distributing a concise educational leaflet unique to this project on childhood/adolescent ASD safety risks, and, in doing so, aimed to answer the following question: How do pediatric healthcare providers perceive a new, concise education leaflet related to safety risks associated with pediatric ASD? This project created a unique concise leaflet for distribution with the following aims: 1) determine the level of provider-perceived usefulness of the leaflet when explaining safety risks associated with pediatric ASD to parents/caregivers, 2) explore how healthcare providers


perceive their current printed teaching materials associated with pediatric ASD, and 3) explore provider attitudes toward the new leaflet.

**Theoretical Framework**

Pender’s health promotion model is often applied to plan for and change unhealthy behaviors and promote health. Pender’s health promotion theory defines health as not just being free of disease, but including measures taken to promote good health, which includes the patient’s own view of themselves and their lifestyle (Petiprin, 2016). The model can be applied to both the individual patient, as well as the family and community. The model identifies background factors that influence health behavior, which assists the healthcare provider in understanding the determinants of health behaviors as a basis for educating to promote healthy lifestyles. Using the model and working collaboratively with the patient or caregiver, the provider can assist to achieve a safe and healthy lifestyle. Health promoting behaviors should result in improved health, enhanced functional ability and better quality of life at all stages of development (Khoshnood, Rayyani & Tigrari, 2018). Pender’s theory applies to this project, as the healthcare provider utilizes printed materials (in this case, a leaflet) to educate parents and caregivers on the safety risks associated with childhood/adolescent ASD, in an effort to promote a safer and healthier environment for the child.

The expectancy-value theory and the social cognitive theory both underlie Pender’s Health Promotion Model (Khodaveisi, Omidi, Farokhi, & Soltanian, 2017). The expectancy-value theory is based on the idea that the course of action will likely lead to the desired outcome, and that this outcome will be of positive value (Khodaveisi, Omidi, Farokhi, & Soltanian, 2017). This can be applied to this project in a sense that, if the parent/caregiver is educated on safety risks, a safer environment will be created for the child. The social cognitive theory describes the
concept of one's perceived ability to carry out a particular course of action. Pender predicts that a high confidence level in the patient and caregivers will lead to a greater likelihood that the behavior will be performed. Applied to this project, if a parent/caregiver is educated, they can anticipate potential and expected safety risks, therefore they will be more confident in intervening and creating a safer environment for the child. As Pender intended, the theory guides the provider through teaching at the parent and caregiver level to motivate them to participate in health and safety promoting behaviors, which increases health and safety outcomes for the patient.

**Literature Review**

There are a number of risk factors associated with ASD which occur at higher rates in children and adolescents, resulting in higher injury rates. Since this project created a safety leaflet for this population, these safety risks were reviewed in detail through a review of the literature. In one noteworthy study, Guan & Li (2017) analyzed data from the multiple cause-of-death data files in the National Vital Statistics System from 1999 to 2014 to examine epidemiological patterns of injury fatalities in individuals with a diagnosis of autism; they found that autism was associated with a significantly increased proportionate mortality from unintentional injury. Results indicated that deaths from individuals with autism were nearly three-times as likely as were deaths in the general population to be caused by unintentional injury (Guan & Li, 2017). The excess proportionate mortality due to unintentional injury was particularly pronounced in autistic children younger than 15 years of age and for three specific causes: drowning, suffocation, and asphyxiation. Together, these three causes of death accounted for 79.4% of the total injury mortality in children with autism (Guan & Li, 2017).
In a study that examined caregiver-reported medically-attended injuries among two-and-one-half to six-year-old children with ASD compared to general population, DiGuiseppi et al. (2018) found that injuries were most common among children with ASD. Researchers found that the most common nature of injury specified by caregivers was open wound, followed by fracture, which together accounted for about half of injuries. Where specified, falls were the most common mechanism of injury, accounting for almost 60% of injury mechanisms, followed by being “struck by or against an object or person”. Anderson et al. (2012) collected information on elopement (wandering) frequency, associated characteristics, and consequences via online questionnaire of caregivers of children with ASD. Results showed that nearly half of children with ASD were reported to engage in elopement behaviors, most commonly from their own home. Of those who went missing, 24% were in danger of drowning, and 65% were in danger of traffic injury (Anderson et al., 2012).

Similarly, Kalb et al. (2016) characterized emergency department visits among children with ASD in an attempt to examine differences in the proportion of ED visits that are due to injury among children with ASD and those without. They also examined differences in the method and intent of injury-related ED visits. Using data from the 2008 Nationwide Emergency Department Sample, Kalab et al. (2016) found that over a quarter of the visits among those with ASD were related to injury. In a multivariate analyses, the odds of injury-related visits was 54% greater among those with ASD compared to those without ASD. In general, they found that the most common types of injuries for all visits were fall and being struck by or against, with these two injuries being more likely to occur in the ASD population. Visits were also more likely to be associated with poisoning or suffocation, and less likely to be related to motor vehicle accidents or firearms when compared to the visits of non-ASD children. Kalab et al. (2016) also found
that, compared to all other pediatric injury-visits in the US, visits among children with ASD were over 5 times more likely to be due to self-inflicted injury and more than 2.5 times more likely to be due to poisoning. Injuries incurred by children with ASD were also more likely to result in hospitalization.

The above literature findings indicate that safety education specifically addressing risks associated with wandering, drowning, suffocation, asphyxiation, self-injury, falling and being struck, and poisoning, be made readily available for caregivers of children with ASD. Considering the significant increase in safety risks associated injury with children with ASD, health care providers have a duty to educate caregivers on these risks, and how to best manage and mitigate them in order to achieve best health outcomes (Paterick, Patel, Tajik & Chandrasekaran, 2017). To date, there is no study that has explored healthcare provider current use or preferences for printed education materials regarding safety risks for children with ASD, with limited research available on provider preferences for education material alone. However, there are studies that have explored provider preferences for printed education materials in other clinical specialties.

For example, in their sub-study, Kasting, Lake & Vadaparampil (2016) used survey data from Pediatric and Family medicine physicians in Florida to assess the current use of educational materials regarding HPV vaccination, and preferences for HPV vaccination patient educational materials. The survey contained 49 questions and subjects were randomly selected from a mailing list of Florida-based pediatric and family medicine physicians provided by the American Medical Association Physician Master-file. The results indicated that pediatricians were more likely to provide education materials than were family medicine practitioners, with the preferred source being concise fact sheets (Kasting, Lake & Vadaparampil, 2016). When asked about
preferences for targeted materials, 63.2% of providers preferred information targeted towards parents. Though it is beyond the scope of this study, considering over three-quarters of physicians in this study indicated they preferred using brief factsheets as a resource when conducting education, these results suggest that using brief, easy-to-explain, and accessible information for parents may be providers’ preferred method of printed education material.

Another study employed a qualitative method to explore primary care provider preferences for the design and content of printed education materials, and determined key attributes that may increase their usability and uptake (Grundniewicz, Chattcharyya, McKibbon & Straus, 2016). Researchers held 90-minute focus groups with actively practicing primary care providers (n=13) who were recruited by mass fax and email. Through thematic analysis, results showed that providers prefer short, specific, concise documents of no more than one to two pages, because they were perceived as being easier to use. Simplicity of materials was also expressed to be important, with many providers preferring printed education materials without lengthy backgrounds or scientific explanations, stating they should use a simple and clear design for easy reference. Color, laminated education materials were reported as being most likely to be kept, stored, and used more frequently. The providers in this study expressed that many patients want to be actively involved in their care, but that they lack user-friendly materials that can be tailored to individual consultations.

**Methods**

**Design**

A quantitative approach was used by administering a cross-sectional survey to pediatric healthcare providers to determine the level of perceived usefulness of the safety leaflet which
was developed for this project. Considering the small sample size, this project is considered to be a pilot study.

**Sample**

Healthcare providers who care for children/adolescents (ages 2-15) with ASD at a large primary medicine pediatric practice were the subjects for this project. The practice consists of four locations, in both suburban and urban settings, and serves a large population of patients with ASD. This project attempted to recruit a sample-size of 19 providers (13 physicians; 6 nurse practitioners). To be included in this study, surveyed providers must actively practice within this pediatric practice. Providers were not excluded based on length of time in practice, gender, or age. Participation in this project was voluntary, and providers did not receive any compensation for completing the survey. If a provider chose not to participate in the survey, they simply did not complete or return the survey. For the purpose of this study, healthcare provider was defined as a doctor of medicine or osteopathy, nurse practitioner, physician assistant, clinical psychologist, or a clinical social worker who is authorized to practice in the State of New York.

**Leaflet Development**

An all-inclusive safety education leaflet was developed based on a review of the literature. Face validity, readability, and clarity of survey questions were assessed by agreement of the principle investigator and an advising psychiatric/mental health nurse practitioner. The literature findings indicated that safety education specifically addressing risks associated with wandering, drowning, suffocation, asphyxiation, self-injury, falling and being struck, and poisoning, be made readily available for caregivers of children with ASD; all of these risks were addressed in the leaflet. The literature also indicates that the impact on knowledge is improved when the leaflets are concise, precise, short, and can be easily accessed by the caregiver for
continuous reinforcement, so this was taken into considering during design and development.

See Appendix B for proof of developed leaflet.

**Data Collection**

Leaflets along with surveys were hand-delivered to the medical director of the practice, and were distributed at an “all provider” meeting by the director. Consent for participation in the project was included with the survey (See Appendix C). Participating providers were provided with both a link to complete the survey electronically, as well as a printed copy; either form of the survey was acceptable and was based on provider preference. After distribution of the leaflet and survey information, the providers had one month to examine and utilize the leaflet in practice before having to complete the survey. Data were collected and analyzed after one month.

**Measures**

A questionnaire was developed based on a review of the literature (See Appendix D). Face validity, readability, and clarity of survey questions were assessed by agreement of the author and an advising psychiatric/mental health nurse practitioner. The survey questions were not tested prior to administration. The primary endpoint of this project was healthcare providers’ perceived usefulness of the new leaflet. Surveyed demographic variables of subjects included categorized options for: gender, and professional practicing title; and interval options for age, number of years in current practicing title, and number of years in pediatric practice. The level of provider-perceived usefulness was evaluated by the question, “As a whole, how useful do you feel the leaflet would be when you were explaining the safety risks associated with childhood/adolescent ASD to parents/caregivers?” Answers to this question were rated on a 4-point Likert-type scale ranging from 1 (not at all useful) to 4 (very useful). Usefulness of
providers’ usual safety education materials were evaluated using the same method by the question, “As a whole, how useful do you feel your current education handouts are when explaining the safety risks associated with childhood/adolescent ASD to parents/caregivers?”

In the survey, providers were asked to report on 8-items based on their experiences and attitudes after receiving the leaflet. Healthcare providers were asked to rate their level of agreement with each of the 8-statements using a 5-point Likert-type scale, with scores ranging from 1 (disagree) to 5 (strongly agree). Survey items asked the provider to evaluate the leaflet’s ease of use, assess their attitudes toward the leaflet, and evaluate their intent to use the leaflet in their practice.

Analysis

Frequencies and percentages for demographic variables and survey responses were calculated using SPSS. Specifically, this project was most interested in the frequency and percentage of providers that find the leaflet “useful” and “very useful,” and “agree” and “strongly agree” in regard to the survey attitude statements. This project also aimed to investigate relationships between the perceived usefulness of the leaflet in relation to demographic factors such provider age, number of years in practice, and practicing title. Cross tabulations were utilized to examine relationships between these demographic variables and survey responses to investigate whether any particular age group, number of years in practice, or practicing title was more likely find the leaflet useful and/or have positive attitudes toward the leaflet. Chi Square test were used to verify cross tabulation data. Descriptive statistics were calculated prior to analysis to ensure all data was within range.

Ethical Considerations
Consent for the project was obtained through the University at Buffalo’s Institutional Review Board (IRB) (See Appendix A for IRB Approval form). Approval for the participation in this project was obtained from the pediatric practice prior to IRB project proposal submission. Privacy of survey respondent identity was addressed by preserving anonymity of responses by assigning a unique numeric code to each set of respondent data.

**Results**

**Sample description**

Leaflets and surveys were distributed to 19 providers. 13 responses were received. Of the 13, two respondents did not include their demographic response sheets in their mailed responses, but did respond to survey questions. Two survey questions were also left unanswered, presumably by mistake, on two separate written surveys. Missing data was omitted from final statistical calculations. See Table 1, for complete demographic characteristics of the survey respondents.

[Insert Table 1 here]

**Perceptions toward the leaflet**

Overall, the majority of providers reported finding the new leaflet “very useful” (n = 7, 58.3%), and “useful” (n = 3, 25.0%), with a small number of respondents reporting it as “slightly useful” (n = 2, 16.7%). See Table 2 which reports provider usefulness of the leaflet. Most providers reported the usefulness of their current education material as “not useful at all” (n = 5, 38.5%), and only “slightly useful” (n = 5, 38.5). See Table 3 which reports provider usefulness of current education materials.

[Insert Table 2 here]

[Insert Table 3 here]
When examining attitude statements responses, over three-quarters of the sample “strongly agreed” or “agreed” with the attitude statements, with the highest levels of agreement being that the leaflet was visually appealing, would help parents to understand the safety risks associated with pediatric ASD, and that it would be appropriate to give caregivers to take home. See Table 3, which summarizes providers’ reported attitudes, examining the frequency of “strongly agree” or “agreed” with statements toward the leaflet.

[Insert Table 4 here]

Cross tabulations and Chi Square identified the following significant relationships in responses: 1) All providers who identified as having been in pediatric practice between 10-15 years reported the new leaflet as being “very useful”, whereas those who identified as practicing in pediatrics greater than 20 years did not report the same consistency of usefulness ($X^2 (2) = 6.667; P = 0.036$); 2) All nurse practitioners “strongly agreed” that the leaflet would supplement their discussion of safety risks well, whereas agreement was less consistent amongst physicians ($X^2 (2) = 7.219; P = 0.027$); 3) All nurse practitioners “strongly agreed” that the leaflet would help parents understand the safety risks, whereas agreement was less strong amongst physicians ($X^2 (1) = 4.950; P = 0.026$); 4) Providers who have been in their current practicing title for over 20 years found their current education materials to be “not at all useful”, whereas agreement was less consistent amongst providers practicing in their title for less than 20 years ($X^2 (4) = 10.267; P = 0.036$). There was no statistical significance between any other demographic variables and survey responses.

**Discussion**

The findings of this study show that pediatric providers who care for children/adolescents with ASD perceive a new, concise, safety education leaflet to be useful. The providers also
reported positive attitudes towards the leaflet. Over 80% of providers in this study indicated finding the new safety education leaflet to be “very useful” or “useful” when explaining the safety risks associated with childhood/adolescent ASD to parents/caregivers. Moreover, 77% of respondents found their current education materials to be only “slightly useful” or “not useful at all,” with a greater proportion of those providers practicing in their current title over 20 years. These findings are consistent with the research that states, providers prefer education materials that are brief, easy-to-explain, and accessible information targeted toward parents/caregivers (Kasting, Lake & Vadaparampil, 2016).

The findings also indicate that nurse practitioners and physicians have different attitudes toward whether the leaflet would supplement their discussion of safety risks well, as well as their agreement that the leaflet would help parents to understand safety risks. This difference in attitudes may suggest that nurse practitioners and physicians have different preferences regarding written education materials for patients and caregivers, and perhaps different views on caregiver education.

As Pender intended, the Health Promotion theory provided the framework for this study by the guiding the provider through teaching at the parent and caregiver level. In this case, the provider used a printed education leaflet, to motivate the parent/caregiver to participate in health and safety promoting behaviors, which increases health and safety outcomes for the patient.

**Conclusion**

**Implications**

To date, this is the first study that has explored healthcare provider perceptions of printed education materials regarding safety risks for children with ASD. This leaflet, which was developed for this project, was perceived as useful, and can help healthcare providers educate
parents and caregivers of pediatric patients with ASD by facilitating understanding of the unique safety risks within this population, as well as help to understand measures they can take to mitigate injury. Examining providers’ perceptions of education materials aids in the development and future use of patient and caregiver education materials.

Healthcare providers in this practice can take the results from this study and use them to improve their deliverability of safety education within their practice. Considering the number of participants who felt that their current education materials were not useful, the practice should continue to explore perceptions on investing in new materials, as well as exploring the varying opinions between nurse practitioners and physicians. The positive attitude responses toward this leaflet may suggest that providers prefer education materials that are brief, concise, easily assessable to caregivers. The providers are also in a unique position to develop or explore education materials that they feel are appropriate and easy for the caregiver to understand. Results of this study will be disseminated to the practice’s medical director and a time to distribute results to providers in a meeting will be arranged, providing opportunity for open forum.

While this project can relate to most of the DNP essentials, the main focus is on meeting DNP essential III -Clinical Scholarship and Analytical Methods for Evidence-Based Practice. Application of this essential involves the translation of research into practice and the dissemination and integration of new knowledge to guide improvements in practice and outcomes of care. The Advanced Practice Role Nurse (APRN) is prepared to critically appraise and apply relevant findings from this study (AACN, 2006). Alongside other healthcare providers, as leaders in policy development, advocacy, and education, the APRN is in a unique position to provide leadership in the development of educational programs and policies designed
to support the education needs of those caring for children with ASD (AACN, 2006). Practice environments where providers provide evidence-based created education materials to caregivers, not only has the potential to improve the quality of education received, but also has the ability to mitigate injury and deaths due to unintentional injury for children/adolescents with ASD.

**Strengths and Limitations**

To date, this is the first study that has explored healthcare provider perceptions of printed education materials regarding safety risks for children with ASD, so it contributed to the literature. Because it was a small sample, the research question was able to be addressed in a relatively short amount of time, with limited resources. Examining providers’ perceptions of education materials aids in the development and future use of patient and caregiver education materials. The survey can be duplicated, as questions remain relevant for examining perceptions on various other education tools.

While this project provided significant new information on providers perceptions, there are some limitations. First, due to the small sample size, the responses obtained may not be representative of the entire population. The providers surveyed were from a single geographic location, and one medical practice, which also limits the generalizability of the findings. Providers may have provided answers they viewed as socially desirable; however, the survey anonymity likely reduced this bias. This project is also limited in scope to providers perceptions and does not examine behavior within clinical practice, or personal opinion beyond the scope of the survey questions. Despite these limitations, this study adds substantially to the literature.

**Recommendations**

Future research should focus on the development and testing of new pediatric ASD-specific safety education materials. Qualitative research should examine perceptions and
preferences of providers beyond limited survey responses. Larger sample sizes should be utilized to investigate perceptions and attitudes toward future education materials. Through the development of additional, concise, education leaflets, providers will have an option in the printed education materials they use when educating caregivers and parents. It may also be beneficial to investigate preferences and opinions regarding education materials amongst a diverse sample of providers, including registered nurses, in order to increase utilization of new, all-inclusive, accessible, education materials in practice. Additional research should be conducted examining differences in perceptions and preferences amongst nursing staff, and physicians. Future studies which examine provider perceptions of printed education materials should consider meeting with providers prior to material dissemination to educate them on the use of the education tool itself; this may increase ease of understanding of the tools and encourage participation.
References


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*Usefulness of Leaflet*

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Table 3

*Usefulness of Current Education Materials*

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<th>Survey Response</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all useful</td>
<td>5</td>
<td>38.5</td>
</tr>
<tr>
<td>Slightly useful</td>
<td>5</td>
<td>38.5</td>
</tr>
<tr>
<td>Useful</td>
<td>3</td>
<td>23.1</td>
</tr>
<tr>
<td>Total</td>
<td>13</td>
<td>100</td>
</tr>
</tbody>
</table>
Table 4

*Provider Attitudes Toward Leaflet*

<table>
<thead>
<tr>
<th>Survey statement</th>
<th>Strongly agree or agree N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The leaflet...</td>
<td></td>
</tr>
<tr>
<td>was visually appealing</td>
<td>13 (100)</td>
</tr>
<tr>
<td>was easy to understand</td>
<td>10 (77)</td>
</tr>
<tr>
<td>would be easy to use during a consultation/appointment</td>
<td>10 (77)</td>
</tr>
<tr>
<td>would supplement my discussion of safety risks well</td>
<td>11 (84.7)</td>
</tr>
<tr>
<td>would help the parent understand the safety risks associated with ASD</td>
<td>13 (100)</td>
</tr>
<tr>
<td>would be appropriate to give to parents/caregivers to take home</td>
<td>12 (92.4)</td>
</tr>
<tr>
<td>I would recommend this leaflet to other providers</td>
<td>10 (83.3)</td>
</tr>
<tr>
<td>I would utilize this leaflet in my practice</td>
<td>10 (77)</td>
</tr>
</tbody>
</table>
Appendix A

IRB Approval Form
Appendix A

University at Buffalo Institutional Review Board (UBIRB)
Office of Research Compliance / Clinical and Translational Research Center Room 5018
875 Ellicott St | Buffalo, NY 14203
UB Federalwide Assurance ID#: FWA00008824
APPROVAL OF SUBMISSION: EXEMPT DETERMINATION

February 5, 2019

Dear Jessica Clark,

On 2/5/2019, the University at Buffalo IRB reviewed the following submission:

<table>
<thead>
<tr>
<th>Type of Review</th>
<th>Initial Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title of Study</td>
<td>Providers’ Perceptions of a Safety-Related Education Leaflet for Pediatric Autism Spectrum Disorder (ASD)</td>
</tr>
<tr>
<td>Investigator</td>
<td>Jessica Clark</td>
</tr>
<tr>
<td>IRB ID</td>
<td>STUDY00003043</td>
</tr>
<tr>
<td>Funding</td>
<td>None</td>
</tr>
<tr>
<td>Grant ID</td>
<td>None</td>
</tr>
<tr>
<td>IND, IDE, or HDE</td>
<td>None</td>
</tr>
<tr>
<td>Documents Reviewed</td>
<td>HRP-503-Jessica Clark_3.docx, Category: IRB Protocol; Written Survey tool.docx, Category: Surveys/Questionnaires; Clark Leaflet.pdf, Category: Other; Information Sheet.pdf, Category: Consent Form;</td>
</tr>
</tbody>
</table>

The study materials for the project referenced above were reviewed and approved by the SUNY University at Buffalo IRB (UBIRB) by Non-Committee Review. The UBIRB has determined on 2/5/2019 that the research is Exempt according to 45 CFR Part 46.101. There is no expiration date.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the Click system.

This UBIRB determination is given with the understanding that the proposed study design will be followed. If modifications are needed that significantly alter the purpose, design, or data collected, then those changes should be submitted to the IRB to determine if the modifications alter the research such that the criteria for an exempt determination are no longer met. You can create a modification by navigating to the active study in Click IRB and selecting ‘Create Modification / CR’. Otherwise, this study no longer needs to be reviewed by the IRB.

For more information on exemption criteria and categories, see the IRB Toolkit Worksheet: Exempt Determination (HRP-312). If you have any questions about this determination, please contact the IRB.

Page 1 of 2
As principal investigator for this study involving human participants, you have responsibilities to the SUNY University at Buffalo IRB (UBIRB) as follows:

1. Ensuring that no subjects are enrolled prior to the IRB approval date.
2. Ensuring that the UBIRB is notified of all reportable information in accordance with the New Information SOP (HRP-024).
3. Ensuring that the protocol is followed as approved by UBIRB including minor changes which can be made if they do not impact the exempt determination.
4. Ensuring that the study is conducted in compliance with all UBIRB decisions, conditions, and requirements.
5. Bearing responsibility for all actions of the staff and sub-investigators with regard to the protocol.
6. Bearing responsibility for securing any other required approvals before research begins.

If you have questions, please contact the UBIRB at 716-888-4888 or ub-irb@buffalo.edu. Please include the project title and number in all correspondence with the UBIRB.
Appendix B

Safety Leaflet
Appendix B

Safety in Pediatric Autism

Research on childhood autism-related safety shows:
• Drowning, suffocation, and asphyxiation make up for 79.4% of the deaths.
• Nearly half of children wander, usually from their own home; 24% are in danger of drowning, and 65% are in danger of getting hurt in traffic.
• Emergency department (ED) visits for injury were 54% greater than children without autism.
• ED visits for children with autism are over 5 times more likely due to self-injury and more than 2.5 times more likely due to poisoning.
• The most common types of injuries are falls and being hit by an object or person.

Here are a few things you can do to keep your child safe:

Wandering
• Figure out what triggers the wandering.
• Think of things that help your child deal with the triggers to help him/her feel better instead of running away.
• Use locks, security alarms, fencing yard, stop signs on doors, windows, etc.
• Think about using a locating (tracking) device.
• Have your child wear an ID bracelet.
• Teach swimming and water safety.
• Inform your neighbors and first responders.
• Practice traffic safety rules and role-play public outing scenarios.

Poisoning
• Lock-up items that are dangerous if swallowed such as detergents, chemicals, cleaning supplies, pesticides, medications.
• Mark dangerous/poisonous items with a sticker to show that they are poison.
• Post the poison control phone number in a place everyone can see.
Pica
- Keep non-food items your child tries to eat out of sight.
- Put locks on cabinets, closets, or doors that contain possible pica objects.
- Vacuum or sweep floors every day.
- Teach your child that eating items that are not food is dangerous.

Water Safety
- Put safety fences, safety covers, and alarms on doors and windows leading to the pool.
- Remove items that could be used to climb over the fence.
- Teach swimming and water safety
- Use adult supervision when swimming or playing in or near water.

Self Injury
- What causes the behavior? Pain, attempting to communicate, attention-seeking, sensory overload?
- Encourage different things the child could do.
- Check with healthcare provider.

General Household Safety to prevent Injury
- Organize and label normal items around the house
- Hide or wind-up appliance wires and window blind cords
- Attach dressers and tall furniture to the wall to prevent tipping
- Use electrical outlet covers
- Install door/stair gates
- Use window locks and/or guards

Additional Resources:

Autism Society:

Autism Speaks: Creating Safety Plans
https://www.autismspeaks.org/creating-safety-plans-people-autism

Autism Safety Project
https://www.autismspeaks.org/autism-safety-project

National Autism Association: Autism and Safety
http://nationalautismassociation.org
Appendix C

Project Information Sheet
Appendix C

Information Sheet
Invitation to Participate in Research Study and Consent

Introduction
You are being invited to participate in a research study titled “Providers’ Perceptions of a Safety-Related Education Leaflet for Pediatric Autism Spectrum Disorder.” This study is being conducted by Jessica Clark through the University at Buffalo, The State University of New York School of Nursing as part of a required doctoral capstone project in the Psychiatric Nurse Practitioner Doctorate of Nursing Program. This research is intended for healthcare providers who care for pediatric patients, ages 2-15, with Autism Spectrum Disorder. For the purpose of this study, healthcare provider is defined as: a doctor of medicine or osteopathy, nurse practitioner, physician assistant, clinical psychologist, or a clinical social worker who is actively practicing, and authorized to practice in the State of New York. If you are not actively practicing, and your practicing title is not described above, please do not participate in this study.

Purpose
The purpose of this research project is to examine how pediatric healthcare providers perceive a new, concise educational leaflet unique to this project regarding safety risks associated with childhood/adolescent Autism Spectrum Disorder.

Procedure
The procedure involves reviewing a caregiver education leaflet on pediatric safety risks, and completing an online or written survey (your preference) that will take approximately 2-3 minutes to complete. This study will be conducted for 30 days. Surveys must be returned/completed no later than April 5, 2019. Your responses will be confidential and no personal identifying information, such as your name or email address, will be collected. To help protect your confidentiality, the survey does not contain information that will personally identify you. There are no risks associated with participating in this study. You may benefit from participation through learning about safety risks associated with pediatric autism. At least 10 people are expected to participate in this study.

Volunteer Status
Your participation in this study is completely voluntary. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. If you decide not to participate, no further action is required. You have the right to refuse to answer any question(s) within the enclosed survey. You may elect to withdraw from this study at any time by not submitting the questionnaire. If you become upset during the study, simply stop answering the questions. There is no monetary compensation for your participation.

Confidentiality
By completing and returning/submitting the survey you are giving implied consent to the investigators to use your survey data for this study. All of your responses will be reported as aggregate or grouped data. No individual responses will be reported. No personal or health
information will be collected. If results are published or presented in a public forum, your identity will not be disclosed as it is not recorded in any way. Data will be kept in a locked file and the investigator will be the only one with access to this file. In order to monitor this research study, representatives the Office of Human Research protection at the University at Buffalo may inspect the research records. Study information will be stored for 3 years.

For Further Information
Any questions, concerns or complaints that you may have about this study can be answered by the principle investigator, Jessica Clark at (248) 630-5440 (jclark3@buffalo.edu)
This research has been reviewed and approved by an Institutional Review Board (“IRB”). You may talk to them at (716) 888-4888 or email ub-irb@buffalo.edu if:
- You have questions about your rights as a participant in this research
- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You want to get information or provide input about this research.

Instructions for completing the survey
If you choose to participate in this study, you may complete either the written or electronic survey, according to your preference.

Written survey: Please complete the attached survey, and mail back to principle investigator using the attached pre-addressed and postage-stamped envelope.

Electronic survey: Please continue to the following web-address to complete the electronic version of the survey. To ensure optimal privacy, it is recommended to conduct the survey on a personal computer, and ensure to close all browsers well complete.

https://www.surveymonkey.com/r/AutismSafetySurvey

Consent
By answering questions in the enclosed survey, or continuing to the electronic survey link and submitting them to the researchers, you are acknowledging your understanding of the above information and are consenting to participate in this project
Appendix D

Survey Tool
Appendix D

Please respond to the following demographic questions by marking the appropriate box that best describes you.

1. Age
   18-29
   30-49
   50-64
   65 or older

2. Gender
   Male
   Female

3. Number of years in practice in your current practicing title:
   Less than 5
   5-10
   10-15
   15-20
   Greater than 20

4. Number of years in pediatric practice
   Less than 5
   5-10
   10-15
   15-20
   Greater than 20

5. Practicing title:
   Doctor of medicine or osteopathy
   Nurse practitioner
   Physician assistant
   Clinical psychologist
   Clinical social worker
Below are two statements regarding usefulness of the safety leaflet. Please read each statement and circle the number that most closely indicates to how useful you found the leaflet.

1) As a whole, how useful do you feel the leaflet was when you were explaining the safety risks associated with childhood/adolescent ASD to parents/caregivers?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all useful</td>
<td>Slightly useful</td>
<td>Useful</td>
<td>Very Useful</td>
</tr>
</tbody>
</table>

2) As a whole, how useful do you feel your current education handouts are when explaining the safety risks associated with childhood/adolescent ASD to parents/caregivers?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all useful</td>
<td>Slightly useful</td>
<td>Useful</td>
<td>Very Useful</td>
</tr>
</tbody>
</table>

Below are eight statements regarding your attitude toward the safety leaflet. Please read each statement and circle the number that most closely indicates to your level of agreement.

The leaflet:

1) was visually appealing

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2) was easy to understand

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3) was easy to use during a consultation/appointment

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4) would supplement my discussion of safety risks well

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
5) would help the parent understand the safety risks associated with ASD

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

6) is appropriate to give to parents to take home

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

7) I would recommend this leaflet to other providers

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>

8) I would utilize this leaflet in my practice

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Neutral</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
</tbody>
</table>
Copy of Oral Defense Slide Deck

5/2/19

Introduction
- Career experience with students with autism spectrum disorder (ASD)
- Therapists need for early intervention
- Provider's expressed need for better safety education and resources
- Current knowledge
- Too lengthy
- Not ideal for students
- Referral for behavior
- Address for students that aggressive acts hang on the refrigerator

Background
- Fear reduction
- Social stories
- Weight
- Group works with students (2018) Gauthier, C., Gauthier, F., & Gauthier, B.
- Knowledge is improved by teachers (2018) Keng, N., & Franco, A.

Purpose
- How do pediatric therapists provide in-service sessions on the need for students with autism spectrum disorder (2017) with Autism Spectrum Disorder (2017)
Theoretical Framework
- Theory: health promotion model, health literacy, and health behavior
- Environment: influence on health behavior
- Policy: role of health promotion in health promotion

Ethical Considerations
- Consent
- HIPAA
- Anonymity

Methods

Setting and sample
- Primary: medicine patient education
- Site: hospital
- Participants: patients with ASD
- Study: cross-sectional study
- Sample size: 50 (50 participants, 6 to 15 years of age)
- Eligibility: consent from parent or caretaker
- Data collection: self-report
- Data analysis: descriptive statistics

5/2/19
Leaflet development
- Qualitative: Developed based on review of literature
- Wandering
- Shoving
- Suffocation and Asphyxiation
- Self-injury
- Fall or being struck
- Inflicting
- Studies indicate that knowledge is improved when messages are concise, clear, and can be easily accessed by the caregivers

Data Collection and Measures
- Survey developed based on literature
- Face validity, reliability, and content assessment
- Demographic variables
  - Age, gender, number of years in practice, professional title
- Items pertaining to knowledge, confidence
- Toolkit identification
- Additional items assessing:
  - Dissemination of information
  - Outcomes of implementation
  - Ease of implementation, fit with the leaflet in practice

Survey
Methodology
- Quantitative approach
- Cross-sectional survey
- Pilot study
- Leaflets and surveys were first delivered together in a meeting
- Disseminated and piloted survey
- One month deadline

Data Analysis
- Frequenst and percentages for demographic variables and focus measures will be calculated using SPSS
- Content analysis