

Spring 6-11-2021

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Prevention of Shaken Baby Syndrome Among High-Risk Neonates:

Program Implementation and Evaluation

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Abstract

Background: Studies suggest that the implementation of high-quality education and support services for caregivers may reduce the incidence of unplanned harm to infants and young children under high-stress circumstances.

Purpose: This study evaluates the usefulness of the Period of PURPLE Crying program in a high-acuity NICU at The University of Chicago Comer Children's Hospital based on six measurable objectives.

Methods: The study utilized a Likert-style pretest-posttest survey design to evaluate how the Period of PURPLE Crying program was perceived by NICU nurses. Nurses were educated on the program content during an in-service aimed to teach participants how to utilize the Period of PURPLE Crying program materials to support and educate families about Shaken Baby Syndrome (SBS).

Results: The intervention effectively increased nursing confidence in the delivery of the SBS and Abusive Head Trauma (AHT) education and increased accessibility to available resources pertaining to SBS and AHT. Questions pertaining specifically to the Period of PURPLE Crying presented exclusively on the posttest were met with an overwhelmingly positive response, with majority (n=33, 97%) of respondents agreeing that the intervention was useful in standardizing SBS education, providing meaningful, effective information on this topic area, and delivering SBS and AHT information in a timely manner.

Introduction

The Centers for Disease Control and Prevention (CDC) reports previously describe how “excessive frustration and exhaustion can lead individuals to a breaking point” leading to Shaken Baby Syndrome (SBS) and Abusive Head Trauma (AHT) in infants (n.d., p. 4) (1). The implementation of high-quality education related to SBS and AHT coupled with support services for caregivers may reduce the incidence of unplanned harm to infants and young children under high-stress circumstances.

Incidence

Shaken baby syndrome (SBS) is the leading cause of child abuse-related deaths in the United States (US) and most often occurs in infants less than 6 months of age (National Center on Shaken Baby Syndrome, 2020) (2). Approximately 1,300 cases are reported each year in the U.S., with nearly 80% of survivors suffer long-term disabilities and proves fatal for one out of four victims (National Center on Shaken Baby Syndrome, 2020) (2). Data on this problem is likely an underestimate as many cases remain unreported and undiagnosed (National Center on Shaken Baby Syndrome, 2020) (2). Abuse of this nature occurs when an infant’s caregiver becomes excessively frustrated, with a higher incidence among those with disproportionate hardships or relationship problems that challenge coping methods (New York State Department of Health, 2010) (3). Other risk factors include those with unrealistic expectations related to normal infant behaviors, individuals that were abused or neglected as a child, domestic violence victims, single parents, preterm infants, children with disabilities, multiples, infants less than 6 months old and infants that cry inconsolably on a frequent basis (CDC, n.d.) (1).

Prevention

The Period of PURPLE Crying program, referred to throughout this publication and much of the literature to date as the PURPLE program, is an education program aimed to reduce the incidence of SBS and AHT through education and caregiver support during period of increased infant crying (National Center on Shaken Baby Syndrome, 2020) (2). A study in British Columbia evaluated a sample of 354,477 parents and concluded that the PURPLE program was effective in reducing hospital admissions related to SBS and AHT by 35% for children ages two years and under over an eight-year period (Barr et al., 2019) (4). This hallmark study emphasizes the value of widespread adoption of standardized, preventative education related to SBS and AHT. Another large-scale study conducted in North Carolina across 86 healthcare entities found that 90% of parents receiving the PURPLE program materials recalled the main constructs two months after having received the intervention and reported an increase in behaviors such as walking away when the infant is inconsolable (Nocera et al., 2016) (5).

Despite these findings, just eighteen states across the U.S. have adopted the program state-wide, see figure 1 in Appendix C (National Center on Shaken Baby Syndrome, 2021) (2,3). The universal adoption of this program among healthcare and community settings across the nation may improve coping methods for parents and caregivers, offer ongoing support, and reduce the incidence of SBS and AHT.

Cost Implications

The cost of SBS and AHT per case accounts for millions in healthcare spending (National Center on Shaken Baby Syndrome, 2020) (2). Visits to the emergency department are one of the key drivers of cost for SBS and AHT. Barr et al. (2015) (6) found that the implementation of the PURPLE program in British Columbia decreased ED visits related to crying episodes for well

babies by 29.5%. Not only does this contribute to better health outcomes for families, but also reduces the overall cost of such visits for the healthcare system.

Study Purpose

The purpose of this project was to evaluate the usefulness of the PURPLE program in a high-acuity Neonatal Intensive Care Unit (NICU) at The University of Chicago Comer Children's Hospital. Prior to the implementation of this pilot study, SBS and AHT were routinely discussed as a part of patient education, however, this practice was carried out with minimal guidance, standardization, or clearly defined objectives.

Methods

Study Design

The study utilized a Likert-style pretest-posttest survey design to evaluate how the PURPLE program was perceived by NICU nurses who agreed to utilize the PURPLE program content to educate parents and caregivers. The Likert-scale ranged from one (strongly disagree) to seven (strongly agree). See Appendix A for complete survey content. Surveys were developed for this study and distributed using the Qualtrics software. The proposal was approved by the University of Chicago Institutional Review Board (IRB) as well as DePaul University's IRB. The University of Chicago's IRB served as the lead site for overseeing this project. IBM SPSS statistics software was used to analyze data.

Implementation

Recruitment was completed by following a script asking nurses to partake in an in-service education aimed to teach participants how to utilize the PURPLE program materials to educate families about SBS. At the start of the in-service presentation, participants completed a

confidential, Likert-style pre-intervention survey on an iPad or personal smart phone device that evaluated their perception of SBS, knowledge surrounding this topic area, and demographics. The in-service education reviewed the most common cause of SBS and AHT, timeframes of increased infant crying, and data on the incidence of such trauma in correlation with periods of increased infant crying. Nurses were asked to give parents and caregivers the PURPLE program pamphlet, review the education, and direct them to the smart phone application to watch the program's video content. After delivering the intervention for approximately four to six weeks, participants received the post-intervention survey link via email or text message with the same six Likert-style questions on the pre-intervention survey plus an additional three questions specific to the PURPLE program content. Participants were given a link to a free CEU related to the program content after completion of the study as an appreciation for participating in this project.

Resources

The purchase of the PURPLE program materials was required to deliver this project. Cost of these materials was \$2.00 per pamphlet and app code couplet. A total of 500 copies of these materials were purchased for a total cost of \$1,000.

Measures

Measurable objectives for this project included: (1) nursing knowledge about SBS and AHT (*pretest posttest question one*), (2) nursing confidence in delivering SBS and AHT education (*pretest posttest question two*), (3) accessibility to resources related to SBS and AHT (*pretest posttest question six*), (4) functionality and efficacy of SBS/AHT education (*pretest posttest question four, posttest questions eight and nine*), (5) perception of the value of SBS and

AHT education in the NICU (*pretest posttest questions three and five*), and (6) message consistency when delivering education about SBS and AHT (*posttest question seven*). See Appendix A for complete survey content used to measure these objectives.

Results

The study results are summarized in this section. Each participant did not respond to every question on the pretest and posttest surveys. See Appendix B for all frequencies and means.

Study Sample & Setting

Data was collected from February to April 2021. Among the participants in this study, 47 individuals responded to the pretest survey, but only 34 participants responded to the posttest for a response rate of 72%. Demographic data of participants is detailed in Appendix B, Table 1.

Nursing Knowledge

The majority (n=44, 93.6%) of respondents on the pretest answered positively to “I feel knowledgeable when it comes to shaken baby syndrome,” with a mean score of 5.70. Similarly, the majority (n=33, 97%) of posttest respondents agreed to a slightly higher degree, with a calculated mean score of 6.0. Despite this increase in the mean score, comparative analysis using the Wilcoxon matched pairs test determined this change was not statically significant (p=.792).

Nursing Confidence

The majority (n=40, 86.9%) of pretest respondents answered “I feel comfortable discussing SBS with parents and caregivers of NICU infants” with an overall agreeable response and a mean score of 5.61. The majority (n=33, 97.1%) of posttest respondents reported an increase in confidence, with a calculated mean score of 6.24. Comparative analysis using the

Wilcoxon matched pairs test confirmed this change to be statistically significant ($p=.016$), concluding that the intervention effectively increased nursing confidence in discussing SBS and AHT with families and caregivers.

Resource Accessibility

In response to “I am aware of available resource for families and caregivers about shaken baby syndrome,” pretest responses were largely mixed with a mean score of 3.85 and only a 42.6% agreeable response. Posttest responses reflected a significant change, with a mean score of 5.97. Wilcoxon matched pairs confirmed that this change was statically significant ($p=<.001$), concluding that intervention effectively increased SBS and AHT resource awareness for nurses in the study.

Functionality and Efficacy of SBS/AHT Education

Just over half ($n=32, 68\%$) of pretest respondents agreed that “time constraints during discharge are a major barrier to discussing shaken baby syndrome,” with a calculated mean score of 4.83. Posttest responses found that nurses felt more strongly about time constraints as a barrier to SBS education post intervention, with 76.4% of respondents reporting agree or strongly agree and a mean score of 5.18. Analysis using Wilcoxon matched pairs confirmed this result was not statically significant ($p=.775$). Despite this finding, ($n=33, 97\%$) of posttest respondents agreed with the statement that the PURPLE program “provides education about shaken baby syndrome in a timely manner,” demonstrating a mean score of 6.44. Paralleling this outcome, ($n=33, 97\%$) of posttest respondents agreed that the PURPLE program “provides effective, meaningful education about shaken baby syndrome,” with a mean score of 6.52. See Appendix B, table 2 for frequency data.

Perception of Educational Value

The majority (n=44, 95.7%) of pretest respondents answered positively to “NICU Nurses should be providing shaken baby syndrome education during discharge teaching,” with a mean score of 6.28. Similarly, the majority (n=33, 97%) of posttest respondents agreed with a calculated mean score of 6.56. Despite an increase in the mean score, comparative analysis using the Wilcoxon matched pairs test determined this change was not statically significant (p=.731).

Similarly, the majority (n=42, 91.3%) of respondents on the pretest answered positively to “Providing education about shaken baby syndrome in the NICU is useful in preventing unplanned harm to an infant,” with a mean score of 6.43. All posttest respondents (n=34, 100%) agreed or strongly agreed, with a calculated mean score of 6.56. Despite an increase in the mean score, comparative analysis using the Wilcoxon matched pairs test determined this change was not statically significant (p=.705).

Consistency of Educational Messages

The majority (n=33, 97%) responded on the posttest with some degree of positivity with responses indicating that the PURPLE program “was helpful in standardizing shaken baby syndrome education on our unit,” with mean score of 6.35.

Discussion

Among the six measurable objectives defined in this study, objectives two and three were met with statistical significance. The intervention effectively increased nursing confidence in delivering education about this sensitive topic area, evident by the statically significant findings among pretest and posttest responses designed to assess this parameter. The intervention also proved effective in increasing accessibility to available resources pertaining to SBS and AHT,

similarly evident with statistically significant findings among comparative responses. Of note, pretest survey responses related to the perceived value of SBS and AHT education infer participants considered education on this topic area valuable prior to this intervention, with posttest responses implying a heightened awareness of this value beyond these initial measures. Moreover, questions pertaining specifically to the Period of PURPLE Crying presented exclusively on the posttest were met with an overwhelmingly positive response, with majority (n=33, 97%) of respondents agreeing that the intervention was useful in standardizing SBS education, providing meaningful, effective information on this topic area, and delivering SBS and AHT information in a timely manner. This study supports the use of high-quality, standardized education as a means of improving the quality and functionality of SBS/AHT education in the NICU setting, however a larger sample would be advantageous in making more definitive inferences about these objectives.

Time Constraints and Patient Education

An increase in the mean score from 4.83 to 5.18 on the pretest to posttest responses when considering time constraints during discharge as a major barrier to discussing shaken baby syndrome may highlight an inherent conflict in healthcare. A study published in *Clinical Nursing Studies* (2017) examined the relationship between nurses' perceived barriers and patient education finding that despite the importance nurses placed on patient education, work overload ranked highest among the barriers to delivering education (Livne et al., 2017) (7). Paralleling this notion, the findings of this study may imply that the use of the PURPLE program may offer nurses a means of making workload at discharge more manageable by imbedding SBS and AHT

education throughout the infant's hospitalization rather than solely discussing this topic at discharge. Further evaluation is necessary to make a definitive inference about this concept.

Clinical Implications

Understanding that infants and children with risk factors such as prematurity, special needs, those under the age of six months that are often inconsolable, and multiple births place infants and young children at a higher risk for AHT and SBS and place further emphasis on the importance of utilizing this education program in the NICU setting, as many NICU graduates can be grouped into one of these aforementioned categories. This study may serve as a tool to reinforce and guide the adoption of the PURPLE program in this and other NICUs settings.

Beyond the NICU setting, considerations for how the widespread adoption of this program at the University of Chicago could impact the community should be acknowledged, as this hospital resides in an underserved community. Demographic evaluation of the medical center's surrounding area further emphasized the need for SBS and AHT education, as disparities prevalent within the community place families at high risk for unplanned infant harm. According to the Journal of Research on Social Work Practice, "Low-income families are significantly more likely to have to contend with domestic violence, as poverty can act as a fueling factor in this type of conflict" (Slabbert, 2016, para. 1) (8). Data from the United States Census Bureau (2018) reported that 42.1% of households in Chicago are single parent households, compared to 31% across Illinois and 32.7% across the U.S (Statistical Atlas, 2018 (9); U.S. Census Bureau, 2018) (10). This data also concluded that poverty affects 19.5% of households in Chicago, compared to 12.1% in Illinois and 11.8% across the U.S. (U.S. Census Bureau, 2018) (10). Understanding of

this data in relation to identified risk factors for AHT and SBS further emphasize the significance of incorporating high-quality, effective education into healthcare practices.

Strengths and Limitations

Strengths of this study included the utilization of pretest posttest design measures for assessing the quality of this education program. Survey responses were collected anonymously, thereby encouraging authentic results. Limiting factors of this study include the small sample size (n=48) and a lower response rate on the posttest (n=34). Other limitations included user error while entering their pre and posttest ID numbers into the surveys; this factor made matching survey responses more challenging. Despite these limitations, the results of the study inferred statistical significance with two of six measures, reinforcing the validity of this intervention.

Future Research

Although the literature largely supports of the implementation of this program, considerations to the challenges and barriers of implementing a large-scale education program in communities and hospitals alike must be addressed. A study in 2011 utilized cross-sectional surveys to evaluate current AHT educational practices and prevention programs among all North Carolina hospitals and birthing centers to further understand barriers to the adoption of a wide-spread AHT prevention program. This study reported that hospitals experiencing challenges in providing education on AHT were predominantly in rural communities, smaller hospitals, and those with limited access to abundant resources (Nocera et al., 2011) (5).

Throughout the implementation of this intervention, cost to deliver the program was a barrier that nearly disrupted this intervention and would cause this program to be unsustainable

in the long-term without adequate funding. Throughout this project, grant funding was explored as a means of overcoming this barrier and may be a realistic resource for achieving large-scale adoption of this program in the future. Given the commonality of resource challenges among hospitals coupled with the monetary challenges faced while implementing this study, barriers to widespread use of this education program should be acknowledged and further explored.

A study conducted in British Columbia reviewing 64 cases of AHT events from 2002-2014 found that subsequent costs ranged from \$1.6 to \$7.1 million in healthcare spending and a societal cost of \$354,359,080. Comparatively, the PURPLE program costs approximately \$5.00 per infant (Beaulieu et al., 2019) (11). As healthcare continues to shift toward a preventative paradigm, this data strongly emphasizes the need to conduct future research in the U.S. surrounding cost-related barriers to implementing such prevention programs. Additionally, such research offers information to facilitate support from key stakeholders such as policy makers and health care providers, emphasizing that "...investing upstream in well-developed AHT prevention programs, such as PURPLE, not only promote child safety and health, but also translates into avoided costs to society" (Beaulieu et al., 2019) (11). Future research must underpin cost-benefit analysis in the prevention of SBS and AHT to improve health outcomes and reduce future healthcare spending.

Conclusion

The PURPLE program has been well-studied, with evidence suggesting that ongoing support for parents and caregivers can reduce hospital admissions associated with SBS and AHT and have a positive impact on the incidence of SBS and unplanned infant harm (Barr et al., 2019) (4). The purpose of this pilot study aimed to evaluate nursing perception of the PURPLE

program in a high-acuity NICU setting based on six measurable objectives. Two of the six Period of PURPLE Crying objectives showed statistical significance supporting the important goals of this program. To continue improving upon the content and outcomes of the PURPLE program, ongoing evaluation across multivariate settings to further examine the multifaceted nature of unplanned infant harm is critical in the fight against this tragedy and to truly make a meaningful impact on this preventable, dynamic public health issue.

Acknowledgements

The money for this project was gifted as a donation by Dr. Veena Ramaiah in the name of promoting research on this topic area. Thank you again for making this contribution and making this research project possible.

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Appendix A
Survey

Age: 20-30 31-40 41-50 51-60 61-70 71-80
 Gender: Male Female Other Prefer not to answer
 Education Level: Associates Degree Bachelor's Degree Master's Degree Doctoral Degree
 Years of experience as an RN: 0-5 6-10 11-15 16-20 21-25 26-30 30+
 Years of Experience in the NICU: 0-5 6-10 11-15 16-20 21-25 26-30 30+
 Shift: 7a-7p 7p-7a other _____
 How often do you complete discharge teaching: Never Seldom Sometimes Often

	Strongly Disagree (1)	Disagree (2)	Somewhat Disagree (3)	Neutral (4)	Somewhat Agree (5)	Agree (6)	Strongly Agree (7)
1. I feel knowledgeable when it comes to shaken baby syndrome							
2. I feel comfortable discussing shaken baby syndrome with parents and caregivers of NICU infants							
3. NICU nurses should be providing shaken baby syndrome education during discharge teaching							
4. Time constraints during discharge are a major barrier to discussing shaken baby syndrome (i.e., too much other education to provide, not enough time, too many other tasks to accomplish)							
5. Providing education about shaken baby syndrome in the NICU is useful in preventing unplanned harm to an infant							
6. I am aware of available resources for families and caregivers about shaken baby syndrome							
7. The Period of PURPLE Crying program was helpful in standardizing shaken baby syndrome education on our unit**							
8. The Period of PURPLE Crying program provides effective, meaningful education about shaken baby syndrome**							
9. The Period of PURPLE Crying program provides education about shaken baby syndrome in a timely manner** (i.e., able to provide SBS education in a reasonable amount of time within discharge teaching)							

**Included on posttest only

Appendix B

Table 1 *Study Sample*

Demographics of Study Sample		n
Age	20-30	11
	31-40	17
	41-50	6
	51-60	12
	61-70	1
Gender	Male	0
	Female	46
	Other or prefer not to identify	1
Education Level	Bachelor's Degree	35
	Master's Degree	10
	Doctoral Degree	2
Years of experience as RN	0-10	27
	11-20	5
	21-30	9
	30+	6
Years of NICU experience	0-10	26
	11-20	8
	21-30	8
	30+	4
Shift	Day shift	29
	Night shift	6
Discharge teaching frequency	Seldom	17
	Sometimes	21
	Often	9

Table 2 Mean score and frequency summary of pre-and post-survey responses

	Pretest survey mean scores	Frequency (rank)	n	Posttest survey mean scores	Frequency (rank)	n
I feel knowledgeable when it comes to shaken baby syndrome	5.70	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree Total Missing	2 0 1 0 13 19 12 47 0	6.0	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree Total Missing	2 0 0 0 3 16 13 34 0
I feel comfortable discussing shaken baby syndrome with parents and caregivers of NICU infants	5.61	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree Total Missing	1 0 3 2 9 22 9 46 1	6.24	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree Total Missing	0 0 0 1 5 13 15 34 0
NICU nurses should be providing shaken baby syndrome education during discharge teaching	6.28	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree Total Missing	1 0 0 1 3 18 23 46 1	6.56	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree Total Missing	0 0 1 0 2 7 24 34 0
Time constraints during discharge are a major barrier to discussing shaken baby syndrome (i.e., too much other education to provide, not enough time, too many other tasks to accomplish)	4.83	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree Total Missing	0 6 7 2 12 14 6 47 0	5.18	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree Total Missing	3 2 2 1 6 11 9 34 0
Providing education about shaken baby syndrome in the NICU is useful in preventing unplanned harm to an infant	6.43	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree	0 0 0 0 4 18 24	6.56	(1) Strongly disagree (2) Disagree (3) Somewhat Disagree (4) Neutral (5) Somewhat Agree (6) Agree (7) Strongly Agree	0 0 0 0 0 15 19

		Total	46		Total	34
		Missing	1		Missing	0
I am aware of available resources for families and caregivers about shaken baby syndrome	3.85	(1) Strongly disagree	4	5.97	(1) Strongly disagree	0
		(2) Disagree	8		(2) Disagree	0
		(3) Somewhat Disagree	10		(3) Somewhat Disagree	0
		(4) Neutral	5		(4) Neutral	0
		(5) Somewhat Agree	12		(5) Somewhat Agree	9
		(6) Agree	5		(6) Agree	17
		(7) Strongly Agree	3		(7) Strongly Agree	8
		Total	47		Total	34
		Missing	0	Missing	0	
The Period of PURPLE Crying Program was helpful in standardizing shaken baby syndrome education on our unit	NA	NA		6.35	(1) Strongly disagree	0
					(2) Disagree	0
					(3) Somewhat Disagree	0
					(4) Neutral	1
					(5) Somewhat Agree	2
					(6) Agree	15
					(7) Strongly Agree	16
					Total	34
					Missing	0
The Period of PURPLE Crying Program provides effective, meaningful education about shaken baby syndrome	NA	NA		6.52	(1) Strongly disagree	0
					(2) Disagree	0
					(3) Somewhat Disagree	0
					(4) Neutral	0
					(5) Somewhat Agree	1
					(6) Agree	14
					(7) Strongly Agree	18
					Total	33
					Missing	1
The Period of PURPLE Crying Program provides education about shaken baby syndrome in a timely manner (i.e., able to provide SBS education in a reasonable amount of time within discharge teaching)	NA	NA		6.44	(1) Strongly disagree	0
					(2) Disagree	0
					(3) Somewhat Disagree	0
					(4) Neutral	1
					(5) Somewhat Agree	0
					(6) Agree	16
					(7) Strongly Agree	17
					Total	34
					Missing	0

Table 3 *Wilcoxon Matched Pairs Test*

	Pre-intervention Survey	Post-intervention Survey	Z	Asymp. Sig (2-tailed).	Statistical significance
I feel knowledgeable when it comes to shaken baby syndrome	5.70	6.0	-.264	.792	Retain null
I feel comfortable discussing shaken baby syndrome with parents and caregivers of NICU infants	5.61	6.24	-2.412	.016	Reject null
NICU nurses should be providing shaken baby syndrome education during discharge teaching	6.28	6.56	-.344	.731	Retain null
Time constraints during discharge are a major barrier to discussing shaken baby syndrome (i.e., too much other education to provide, not enough time, too many other tasks to accomplish)	4.83	5.18	-.286	.775	Retain null
Providing education about shaken baby syndrome in the NICU is useful in preventing unplanned harm to an infant	6.43	6.56	-.378	.705	Retain null
I am aware of available resources for families and caregivers about shaken baby syndrome	3.85	5.97	-3.438	<.001	Reject null