

St. Catherine University

SOPHIA

Doctor of Nursing Practice Projects

Nursing

8-2018

Implementing a Standardized Process for Autism Screening of Somali Toddlers

Adno Ahmed Gatah
St. Catherine University

Follow this and additional works at: https://sophia.stkate.edu/dnp_projects

Recommended Citation

Gatah, Adno Ahmed. (2018). Implementing a Standardized Process for Autism Screening of Somali Toddlers. Retrieved from Sophia, the St. Catherine University repository website:
https://sophia.stkate.edu/dnp_projects/101

This Doctor of Nursing Practice Project is brought to you for free and open access by the Nursing at SOPHIA. It has been accepted for inclusion in Doctor of Nursing Practice Projects by an authorized administrator of SOPHIA. For more information, please contact sagray@stkate.edu.

Implementing a Standardized Process for Autism Screening of Somali Toddlers

DNP Project
Submitted in Partial Fulfillment
Of the Requirements for the Degree of
Doctor of Nursing Practice

St. Catherine University
St. Paul, MN

Adno Ahmed Gatah

August 2018

ST. CATHERINE UNIVERSITY
ST. PAUL, MINNESOTA

This is to certify that I have examined this
Doctor of Nursing Practice DNP project manuscript
written by

Adno Ahmed Gatah

and have found that it is complete and satisfactory in all respects,
and that any and all revisions required by
the final examining committee have been made.

Graduate Programs Faculty

Name of Faculty Project Advisor

December 28, 2018

Date

DEPARTMENT OF NURSING

© Adno Ahmed Gatah, 2018
All Rights Reserved

SOMALI TODDLERS AUTISM SCREENING

Acknowledgements

I would like to express my gratitude to my advisor Dr. Nanette Hoerr for her guidance and mentorship of this project. Your expertise and feedback were meaningful to the success of this project.

I am also very grateful to Dr. Margaret Dexheimer Pharris for her intellectual humility and knowledge and many insightful discussions and suggestions in this DNP project. You have been an instrumental in making this project a reality. Thank you very much for being awesome!

I would also like to thank Dr. Patricia Finch-Guthrie for her support, patience, and encouragement throughout my DNP education.

Dr. Heather Moulzolf provided valuable feedback and guidance in my DNP education and helped make this project possible. Thank you!

I am also very grateful to Dr. Nasra Giama who has been a resource and provided an insightful feedback in this project. Thank you.

I would also like to acknowledge my DNP Cohort 9, thank you for your thoughts, curiosity and feedback. I cannot wait to see you lead and influence so many in positive ways.

SOMALI TODDLERS AUTISM SCREENING

Dedication

I dedicate this DNP work to my two beautiful daughters (Mumtaz and Ebyan), you are the reason I work hard and dream big. Thank you for loving me unconditionally! I love you dearly!

To my mother who inspired me to dream big and reach my highest potential. Without you, I would have not been able to dream and pursue my goal of higher education. I thank you from the bottom of my heart. To my siblings who supported me always and been there for me. I love each and every one of you! Thank you.

To my husband, thank you for being a friend and a partner for life. Your support, patience and encouragement allowed me to realize my dream. Thank you for your constant support and unconditional love.

This DNP manuscript is dedicated to the memory of my father (Ahmed Gatah). Although he is and was my inspiration to pursue my highest potential and strongly believed in education, he was unable to see my graduation. This is for you dad! May Allah SW take you and keep you the highest level of Jannah. I love you, dad!

SOMALI TODDLERS AUTISM SCREENING

Abstract

Purpose: Autism spectrum disorder (ASD) is a developmental disorder that oftentimes results in significant social, communication, and behavioral challenges. In 2014, the CDC reported that one in 68 children were diagnosed with autism. Hewitt et al. (2013) reported that in Minneapolis, Minnesota, 1 in 32 Somali children ages 7-9 had ASD, a rate higher than any other immigrant population. Early diagnosis and immediate implementation of intensive treatment leads to improved outcomes for children with autism (Carakovac et al., 2016). The purpose of this DNP project is to develop a standardized process for increasing completion and documentation rates of the MCHAT-R for Somali children between ages 16 months to 30 months in a pediatric clinic serving a significant population of Somali children and families.

Problem: The practice problem surrounding this DNP project centers on a pediatric primary care clinic where a standardized process for toddler autism screening does not exist. Screening procedures are inconsistently applied, leaving some children at risk for undiagnosed ASD.

Approach: The DNP student developed a standardized process for increasing completion and documentation rates of the MCHAT-R form for Somali children between ages of 16 months and 30 months. The DNP student and quality improvement (QI) team made incremental changes utilizing the PDSA cycle model as a framework.

Results: Twenty charts were reviewed for pre-intervention and post-intervention. Of the 20 charts reviewed pre-intervention, autism screening was documented in the electronic health records of 35% of 18-month-old and 65% of 24-month-old toddlers. Post intervention, the screening rate rose to 95% of 18-month-old and 85% of 24-month-old toddlers.

Conclusion: Implementing a quality improvement process led by this DNP student resulted increase in autism screening and documentation rate within the pediatric clinic.

SOMALI TODDLERS AUTISM SCREENING

Keywords: *autism spectrum disorder, Somali, autism screening, quality improvement processes, barriers to quality improvement, autism, practice initiatives.*

SOMALI TODDLERS AUTISM SCREENING

Autism spectrum disorder (ASD) is a developmental disorder that causes significant social, communication, and behavioral deficits (Centers for Disease Control and Prevention [CDC], 2014). Autism typically begins in infancy and is often diagnosed during the first three years of life (CDC, 2014). Although the prevalence of autism in the general pediatric population is one in 68 children, rates for Somali children living in Minneapolis, Minnesota is much higher with 1 in 32 children identified as having ASD (CDC, 2014; Hewitt et al., 2013). Additionally, Hewitt et al (2013) noted that in this patient population, children receive diagnoses later as compared to non-Somali children, with a corresponding delay in services and therapies.

Because of the prevalence of this disorder and need for early diagnosis and treatment, it is critical that pediatric providers pay close attention to red flags that often manifest in children with autism. Early diagnosis and immediate implementation of intensive treatment leads to a better prognosis for children with autism (Carakovac et al., 2016). The American Academy of Pediatrics (AAP) emphasizes the importance of early identification of autism through close developmental observation during well-child exam visits (AAP, 2016). The AAP recommends the use of a standardized instrument to screen for autism at 16 to 30-month well exams. The most frequently used screening tool is the Modified Checklist for Autism in Toddlers (MCHAT-R), which is a brief developmental tool used to screen for ASD in children as young as 18 months (Baird et al., 2000). Although, the screening tool is recommended for children ages 16 to 30 months, the clinic that serves as the primary focus of this project administers this questionnaire at the 18 and 24-month well exams.

The Checklist for Autism in Toddlers (CHAT) was the original tool used for autism screening and was developed by Baron-Cohen et al. (1992) for use in Great Britain. The CHAT instrument was modified by Robins et al. (2001) to improve sensitivity and was labeled as the

SOMALI TODDLERS AUTISM SCREENING

Modified Checklist for Autism in Toddlers (MCHAT-R). The MCHAT-R consists of parental responses to twenty questions (Appendix A). If a child screens positive, defined as three or more positive answers, then parents are asked follow-up questions to gather more information regarding examples of at-risk behaviors. If a child scores three or more positive answers during screening, this triggers the need for further diagnostics, monitoring, or evaluations. It is acceptable that a clinician refers a patient for further evaluation and early intervention. The original CHAT and the MCHAT-R are written in English. Robins et al. (2014) screened 16,071 toddlers between 18 months and 24 months at well-child- exam visits in metropolitan Atlanta and Connecticut. When a child's screening results indicated concerns, parents were asked additional follow-up questions. Toddlers whose total score was ≥ 3 initially and ≥ 2 after follow-up had a 47.5% risk of being diagnosed with ASD and a 94.6% risk of any developmental delay or concern (Robins et al., 2014). This screening tool is shown to have adequate sensitivity and specificity (Robins et al., 2014).

In a sample of nearly 19,000 toddlers, aged 16 to 30 months, 54% of children were classified as at risk based on the M-CHAT-R screening tool were diagnosed with ASD, while 98% positive cases also presented with developmental delay or concerns (Robins et al., 2014). The validity and reliability of the MCHAT-R was studied internationally, in non-western countries. In the USA, the MCHAT-R was found to have good inter-rater reliability, re-test reliability, construct validity, and discriminant validity (Scarpa et al., 2013).

Problem Formation and Purpose Statement

A standardized process for administering the MCHAT-R did not occur at the pediatric primary care clinic where this DNP project took place. This primary care clinic is part of a larger health care organization located in the Twin Cities area. Parental understanding of the MCHAT-R

SOMALI TODDLERS AUTISM SCREENING

questionnaire is imperative for accurate results and it was clear that multiple problems with this tool existed in this clinic for Somali parents and their toddlers. For example, parents did not receive consistent instructions for completing the screening tool; variations in clinic workflow provided some parents with adequate time for questionnaire completion, and not others; and staff did not follow a consistent process for collecting data. Early diagnosis of autism and accurate screening data depends on parents' ability to provide accurate observations about behaviors and skills of their child. Close observation of development in the child is critical to the identification of autism (AAP).

The identification of gaps in the autism screening process of Somali children ages 16 months to 30 months in this pediatric primary care clinic provided the information necessary to create and implement a standardized process to improve autism screening for the Somali population. The quality improvement team hypothesized that the creation and implementation of a standardized process (consistent pathway) would lead to improved autism screening rates for Somali toddlers

Theoretical Framework

The Institute for Healthcare Improvement (IHI, 2018) supports the Plan-Do-Study-Act (PDSA) model for quality improvement projects. The PDSA model is commonly used in health care settings for its rapid improvement in real time (IHI, 2018). The PDSA process is a continuous trial-and-study approach that enables organizations to implement change in real work settings (IHI, 2018). According to Varkey, Reller, and Resar (2007) the PDSA model is a process by which a concept or suggested solution for improvement is made and testing is carried out on a small scale before any changes are made to the whole system.

SOMALI TODDLERS AUTISM SCREENING

This model comprises of 4 phases: Plan, Do, Study, and Act. During the Plan Phase, ideas, needs and proposals for improvement are delineated, the team is identified, tasks and expectations are assigned, and measures for improvement are set (IHI, 2018). The Do Phase involves project implementation and documentation of adaptations to the process; followed by the Study Phase that focuses on desired outcomes of the proposed improvement; and the Act Phase refers to the implementation of lessons learned from the previous two cycles of the model (IHI, 2018).

Literature Review

Databases selected for the following literature review include the Cumulative Index of Nursing and Allied Health Literature (CINAHL), Google Scholar, PubMed, and Cochrane. Each of these databases includes current and relevant literature specific to healthcare and provides up to date research about the topic of interest. Keywords for the literature search include the following: *autism, autism spectrum disorder, quality improvement processes, barriers to quality improvement, autism, practice initiatives*.

Ten articles were appraised for this DNP Project using the Johns-Hopkins Nursing Evidence-Based Practice Tool (2017). Four of the articles reviewed were Level 1 studies that included a systematic review and randomized controlled trial (RCTs) with an A/A/B/C/C quality index as described by the Johns-Hopkins Nursing Evidence-Based practice tool. Five other articles were Level 2 with a high quality of A/B/B/C/C (Johns Hopkins Nursing Evidence-Based Practice, 2017). The literature review that follows analyzes research that has used quality improvement processes to address practice problems. I will also discuss the effectiveness of quality improvement initiatives and their impact on practice problems, barriers to practice change, and specific studies that address screening and early identification of ASD.

SOMALI TODDLERS AUTISM SCREENING

Quality Improvement Initiatives Effectively Address Practice Problems

As the following literature review reveals, quality improvement initiatives can effectively address practice problems and have a positive impact on patient care. For example, Akhter, Monkman, Vang, and Pfeiffer (2017) conducted a study using Plan-Do-Study-Act to implement workflow changes. The purpose of this quality improvement project was to improve adult and children's Asthma Control Test (ACT) scores utilizing an Asthma Action Plan (AAP). At the end of the project implementation, asthma control rates increased from 23% to 58% in adults and 45% to 63% in children over twelve months, demonstrating the effective use of PDSA methodologies to address practice problems. Although the findings in this study showed significant improvement in ACT scores in both adults and children, there is a limitation worth considering. For example, there were inconsistencies in style and techniques of asthma education in the two different populations that were participating in the study.

In another study, Asarnow et al. (2005) evaluated the effectiveness of a quality improvement intervention for depression. This study focused on increasing access to evidence-based treatments for depression with specific attention to cognitive-behavior therapy and antidepressant medication compared to "usual care" among adolescents in five urban primary care practices. Similar to the previous study, at the six-month follow up visit, patients in the quality improvement project demonstrated significantly lower depressive symptom scores using the Center for Epidemiological Studies-Depression Scale (CES-D) tool. Results of the Asarnow (2005) study are significant however, there were limitations. These limitations included the lack of random selection and low diversity or ethnic group participation. Therefore, these limitations limit the generalizability of the results to all populations. The results of this study demonstrate

SOMALI TODDLERS AUTISM SCREENING

that a well-conducted quality improvement process can effectively address practice problems and at the same time have a positive impact on patient care.

Walsh et al. (2006) conducted a systematic review synthesizing forty-four articles to evaluate the effects of quality improvement strategies for hypertension management in lowering blood pressure. In their review, Walsh et al. (2006) found that patients in the intervention group experienced reductions in both systolic blood pressure (SBP) and diastolic blood pressure (DBP). Despite the study's promising results, this study's literature review had limitations worth mentioning. For example, Walsh et al. (2006) failed to discern whether specific interventions or strategies were more potent than others and why improvements in blood pressure were higher in small studies than larger studies. However, Walsh and colleagues' (2006) systematic review affirmed that quality improvement initiatives effectively address practice problems. These studies together demonstrated that quality improvement initiatives improve quality of care.

Barriers to Quality Improvement Processes

Despite the growing body of evidence that quality improvement processes yield positive results in quality care as shown in numerous studies, there are challenges and barriers to quality improvement processes. For example, Dixon-Woods, McNicol, and Martin (2012) identified areas of challenge in improving the quality of health care, such as convincing staff that a problem even exists. According to these researchers, when staff does not consider an issue problematic, change is unlikely. In addition, when organizational culture is inadequate and does not support the quality improvement process, this can lead to problems with patient safety and create gaps in care. Dixon-Woods, McNicol, and Martin (2012) address important barriers to the quality improvement process; however, these authors failed to mention the importance of staff engagement and collaboration. If staff is engaged in the identification of the problem and

SOMALI TODDLERS AUTISM SCREENING

designing interventions, then the quality improvement process is more likely to succeed. When staff identify problems and corresponding solutions, there is a tendency to reduce barriers to the change process. Likewise, Dixon-Woods, McNicol, and Martin (2012) failed to highlight the importance of organizational resources - if an organization lacks resources and infrastructure, quality improvement processes are not always a priority.

Another study was conducted by Morelli et al. (2014) utilizing mixed methodology to identify challenges and barriers for developmental screening strategies in urban primary care settings. Themes identified as barriers to quality improvement included lack of time to conduct developmental screening, lack of reimbursement for completing developmental screening tools, and lack of training in the use of developmental screening tools (Morelli et al., 2014). These barriers have detrimental effects on quality improvement and can lead to a delay in early intervention for children. While these barriers to quality improvement processes are essential to highlight, a limitation of this article includes that this study was conducted in a single geographical area making it difficult to generalize to other geographical areas and practices.

The obstacles to quality improvement process and getting quality services are enormous and unnecessary for specific populations such as the population that is the focus of this DNP project. The Minnesota Department of Health (2014) conducted community-based participatory research (CBPR) aimed at identifying barriers that are unique to the Somali population at risk for ASD. System-level barriers identified included long appointment wait list, which led to delay in diagnosis and treatment, difficulties navigating a complex system; and a lack of clear processes within organizations serving Somali children at risk for autism. These specific barriers represent missed opportunities for early identification of Somali children at risk for ASD. Change occurs through the analysis of barriers and identification of solutions. Understanding quality

SOMALI TODDLERS AUTISM SCREENING

improvement processes and potential barriers is necessary for achievement of improved outcomes and system change.

Autism Spectrum Disorders (ASD) and Practice Initiatives

As the following studies emphasize, early screening and identification of ASD offers the best outcomes for children at risk for ASD. Boyd, Odom, Humphreys, and Sam (2010) reviewed the importance of early screening and effectiveness of early intervention for children at risk for autism in their integrative review. Boyd, Odom, Humphreys, and Sam (2010) highlighted the fact that early screening and intervention lead to timely access to services and effective interventions, which in turn leads to better care and improved outcomes for children at risk for autism.

The clinical impact of early ASD diagnosis was also stressed by Elder, Kreider, Brasher, and Ansell (2017) who conducted a review article describing the clinical impact of ASD early diagnosis and its prognosis. In their recommendation, these authors suggested that early diagnosis and intervention leave lasting impacts on the long-term trajectories and quality of life for children with autism. However, Elder and colleagues only highlighted a small range of skills and behaviors, thus, failing to expand on other interventions such as pharmacological, medical, and technological approaches. Therefore, it is difficult to generalize these findings to all children at risk for autism because it is difficult to confirm whether these interventions made a difference in the diagnosis and prognosis of children at risk for autism.

Use of valid and reliable screening tools facilitate early and effective treatment. Campbell et al. (2017) implemented a quality improvement study assessing changes in quality of care for children at risk for Autism Spectrum Disorders (ASD) by process improvement and implementation of a digital version of the MCHAT-R screening form. Their quality metric

SOMALI TODDLERS AUTISM SCREENING

included assessing the accuracy of documentation of screening results and determined if an appropriate action for positive screens (secondary screening or referral) was documented. This quality improvement study revealed significant gains in the accurate use of the MCHAT-R and outlined appropriate step for children with positive screens. Campbell and colleagues demonstrated that quality improvement initiatives aimed at improving the process of screening for ASD can lead to early intervention and improved quality of care for children at risk for ASD. Even though, the Campbell et al. (2017) study revealed significant gains in the completion rate of MCHAT-R and appropriate action, some limitations need to be considered. For example, this study did not include diagnostic outcomes results, which are important for clinical outcome.

In an attempt to improve the proportion of toddlers screened for ASD, as well as physicians' self-efficacy in providing care to autistic children Carbone, Norlin, and Young (2016) designed a quality improvement process aimed at improving the proportion of toddlers screened for ASD, as well as improving physicians' self-efficacy in providing care to these children. At the completion of this quality improvement study, there was a significant increase in screening rates and care for children with ASD. Although the Carbone et al. (2016) study showed significant improvement in the screening rates, this study had some limitations. For example, the researchers relied on participating practices to provide data from chart audits and therefore independent validation of results did not occur.

Finally, Bradshaw, Steiner, Gengoux and Koegel (2015) conducted a systematic review focused on the feasibility and effectiveness of early intervention in infants and toddlers at risk for autism. As highlighted in the previous mentioned studies, early intervention is the best opportunity for optimal development and positive outcomes. Bradshaw, Steiner, Gengoux and Koegel (2015) presented a literature review that included nine articles analyzing participant

SOMALI TODDLERS AUTISM SCREENING

characteristics, intervention approach, experimental design, and outcomes. All of the studies collectively agreed that early intervention is feasible and effective for infants and toddlers at risk for autism, however significant limitations existed within this study, including small sample size (137) and a lack of generalizability.

Despite the limitations in the studies discussed in this paper, the studies included in this literature review supported the effectiveness of quality improvement initiatives and their impact on practice problems. Likewise, these studies revealed barriers to practice change that impact quality improvement initiatives and yet supported the positive effect of early screening and identification of ASD.

Synthesis

As multiple studies have demonstrated it is clear that quality improvement initiatives address practice problems and improve quality of care. However, the threats and obstacles to process improvement must be addressed. Many of these barriers are system issues and care providers are unable to correct these problems without clear and consistent organizational workflow processes.

Implementing consistent workflow procedures and screening practices makes a difference in the early diagnosis and intervention for children at risk of autism. Somali children have higher rates of ASD than other immigrant populations, which makes close developmental observation critical for this particular group. Screening tools such as MCHAT-R are valid screening measures that identify and detect ASD. It is imperative to ensure that clinicians servicing the Somali population can interpret the results and integrate the findings of screening tools. The clinicians serving Somali children at risk for ASD must be able to serve as

SOMALI TODDLERS AUTISM SCREENING

gatekeepers connecting care, while at the same time, bridging gaps that exist at the individual and system level.

Project Implementation

Setting

The project site is an urban primary care clinic that is part of a larger health care organization. The project site employs pediatricians, pediatric nurse practitioners, registered nurses, licensed practical nurses, medical assistants, front desk medical receptionists, and medical professional interpreters. The patient population served in this pediatric clinic is approximately 50% Somali ethnicity.

Project Proposal

The Doctor of Nursing Practice (DNP) student served as the project leader and met with the organizational quality improvement team (QI) to discuss current workflow processes for screening Somali children ages 16 months to 30 months for ASD risk. The team agreed there was a need to assess the organization's processes for autism screening and to identify gaps in current practice. The DNP student proposed using multiple, incremental PDSA cycles as the framework for a structured approach to affect change in the current process. The DNP student and QI project team carried out three PDSA cycles.

Cycle One of PDSA Cycle

During the plan phase of Cycle One, the DNP student assessed organizational need, developed the project proposal, and provided leadership and interdisciplinary collaboration. During this cycle, the DNP student and project advisor discussed the QI process; anticipated barriers to project implementation and how to address conflict management. The DNP student also discussed successful team-building strategies and how to implement newly developed processes.

SOMALI TODDLERS AUTISM SCREENING

The planning phase also involved understanding the current process of obtaining MCHAT-R information, conducting gap analysis, and developing patient surveys. The QI team and DNP student submitted an application to the organization's IRB, which deemed it a quality improvement (QI) project, not requiring committee oversight. Following institutional guidelines, an IRB application was then submitted to St. Catherine University and approval was granted to move forward with this QI project.

Conducting a chart review allowed understanding of the clinic's current process about how Somali parents complete the MCHAT-R. The DNP student identified 20 charts of Somali toddlers, ages 16 months to 30 months whose parents should have completed the paper version of the MCHAT-R. The clinic's process is that support staff are required to send the completed paper MCHAT-R form to the medical record department to be scanned in the EPIC electronic health record. Each chart was evaluated for the following:

- A. Is the MCHAT-R completed for children at 18 and 24 months and scanned into the EPIC electronic health record, under the Media tab?
- B. Is the MCHAT-R form fully and accurately completed?

Analysis of the initial PDSA cycle revealed a lack of a standardized process and clearly articulated workflow for completion and documentation of the MCHAT-R screening tool, supporting the need for the proposed QI project. For example, when reviewing 20 charts for completion of MCHAT-R screening, 65% of children aged 18-months did not have documentation of autistic screening (thirteen of the twenty charts lacked the MCHAT-R form). When examining rates for 24-month olds, 35% of children did not have screening data documented in their electronic medical record (seven of twenty charts reviewed) and it was

SOMALI TODDLERS AUTISM SCREENING

unclear whether clinic staff failed to distribute the form, if parents had not completed the tool for some reason, or possibly the form was completed, but not scanned into the medical record.

Results of this chart review revealed a gap between current autism screening and documentation and inconsistencies in the process used to evaluate developmental milestones for Somali toddlers, ages 16 months to 30 months. Similarly, there was no clear evidence about distribution of screening tools, instructions given to parents on how to complete the form, where the form was to be completed, how much time was allotted for the form to be completed, and when forms would be scanned into the electronic medical record.

The results demonstrated a lack of consistent pathways within the clinic when screening and documenting autism for Somali toddlers. Based on these findings from this early project phase, the DNP student responded by developing a standardized, systematic process for increasing completion and documentation rates of the MCHAT-R for Somali children.

Cycle Two of the PDSA Cycle

At the inception of this project, there were a number of thoughts about why this practice problem existed and many considered it a “parent issue”. For example, since the MCHAT-R is written in English, could it represent a language barrier for Somali parents? There were questions about the MCHAT-R screening tool and cultural congruency for this patient population. Another thought centered on social stigma and hesitancy to have one’s child labelled autistic. To understand these barriers more fully, the DNP student developed a survey to assess Somali parents’ understanding of the MCHAT-R, identify barriers faced when completing the MCHAT-R, and create effective solutions that would lead to an accurate diagnosis of autism.

During this phase, the project team initially hoped ten parents would complete surveys, however later increased this number, resulting in submission of an amendment to the

SOMALI TODDLERS AUTISM SCREENING

University's IRB. Forty-three patient surveys were distributed over a three week period, resulting in a response rate of seventy-two percent. Patient surveys consisted of six questions described in Table 1. An analysis of findings is presented in the discussion section of this document.

Table 1

Parent Survey

Question	Yes	No	Comments
1. Were the questions on the form you filled out easy to understand?	90.2%	9.3%	2 incomplete
2. Did the questions on the form ask you about how you notice how your child usually behaves?	95.1%	4.9%	2 incomplete
3. Were you able to understand and answer these questions about usual behavior?	92.7%	7.3%	2 incomplete
4. I understand why I'm being asked to fill out these forms for my child.	86.8%	7.9%	5 incomplete
5. I understand the importance of being able to answer these questions [MCHAT-R] to the best of my knowledge.	89.2%	8.1%	6 incomplete
6. I understand what my health care team will do with this information.	76.3%	10.5%	5 incomplete

During this project phase, besides surveying parents, the DNP student and QI team created a clinical guide (step by step script) to promote a standardized process for MCHAT-R

SOMALI TODDLERS AUTISM SCREENING

completion. In order to assess perception of this practice change, a pre-survey was developed to gather information about different aspects of MCHAT-R completion from the unique perspective of clinic staff. The pre-survey consisted of four Likert-style questions, including the following:

(1) Forms are mostly filled out by the time the patient is called back to the exam room. (2) Forms are filled out by the time the clinician starts the visit. (3) I have to clarify the questions for the patients. (4) It takes significant effort for me to explain the form for patients.

Cycle Three of the PDSA Cycle

The third PDSA cycle focused on analyzing staff pre-survey data, implementing the clinical guideline and workflow process, and distributing a post-survey to all clinic personnel. Another chart review was completed to evaluate the effect of the DNP intervention. During the Plan phase of this cycle, the DNP student and QI team reviewed the data from the staff pre-survey. Results are described in Table 2 and interpretation of findings follows in the discussion section of this document.

Table 2

Staff Pre-survey

Question	Never	Sometimes	Often	Always
1. Forms are mostly filled out by the time the patient is called back to the exam room**	53.8%	30.8%	15.4%	0%
2. Forms are completely filled out by the time the clinician starts the visit*	53.3%	26.7%	13.3%	6.7%
3. I have to clarify the questions	30.8%	23.1%	23.1%	23%

SOMALI TODDLERS AUTISM SCREENING

for the patients**				
4. It takes significant effort for me to explain the form for patients*	20%	26.7%	13.3%	40%

*N=15

**N=13

As previously mentioned, during Cycle 3 the DNP student and QI team implemented the newly created clinical guide (step by step script) for Somali toddlers, ages 16 months to 30 months, scheduled for well-child visits. The implementation phase occurred over a three week period. The clinical guideline was placed in patient binders, along with other supporting documents.

Following the three week implementation period, a post-survey was distributed to staff to assess whether this newly created clinical guide made a difference in the completion of MCHAT-R form for Somali toddlers, allowing comparison of pre- and post-survey data. Table 3 describes post-survey data and as described above, a discussion of results follows.

Table 3

Staff Post-Survey

Question	Never	Sometimes	Often	Always
5. Forms are mostly filled out by the time the patient is called back to the exam room*	0	71.4%	14.3%	14.3%
6. Forms are completely filled out by the time the clinician starts the visit**	13.3%	33.3%	33.3%	20%

SOMALI TODDLERS AUTISM SCREENING

7. I have to clarify the questions for the patients**	40%	53.3%	6.7%	0%
8. It takes significant effort for me to explain the form for patients*	46.7%	53.3%	0%	0%

*N=14

**N=15

At the conclusion of this project, the DNP student conducted a final chart review to evaluate the effectiveness of the clinical guide and intervention. To remain consistent with the earlier review, twenty medical records for Somali children, ages 18 and 24 months who were scheduled for well-child exams, were selected. Findings of this chart review are presented later in this document.

Evaluation

During the initial PDSA cycle, the team examined and evaluated organizational processes focused on the practice problem. The team discovered a lack of consistent workflow processes surrounding the completion and documentation of the MCHAT-R for Somali toddlers. Results of the surveys from PDSA Cycle Two revealed that the issue of poor compliance with MCHAT-R completion and documentation lay within the organizational system. During PDSA Cycle Three, the team implemented a clinical guide to ensure that a consistent, standardized process and a universal message was provided to all patients regarding the use of the MCHAT tool. It was hypothesized that the guide would assure consistent completion and documentation of the MCHAT-R for Somali toddlers.

The study author believed the process improvement would lead to an accurate diagnosis of autism. To assure that the newly created clinical guide improved the process for completing and documenting the MCHAT- R, the project team created a staff survey. The intent of the staff

SOMALI TODDLERS AUTISM SCREENING

survey was to evaluate changes in practice related to the use of the clinical guide. The results of the staff survey showed an increase in the completion rate of the MCHAT-R before the patient was called back to the exam room. At the conclusion of the project, chart reviews were utilized to assess the effectiveness of the process improvement and the effects it had on the completion and documentation of the MCHAT-R for Somali toddlers, ages 16 months to 30 months.

While the results of the project implementation showed promising results, there were limitations worth mentioning. These limitations include staff resistance to the changes made. Likewise, some of the patients verbalized that their appointments were longer than they had expected. Similarly, providers also felt that they had to wait until the patient filled out the forms completely which made them fall behind in seeing other patients. Finally, nurses who were rooming the patients also felt that when forms were not filled out completely or partially, they had to sit down with patients and help fill out the forms, which they felt was inconvenient.

Despite the above limitations, the development and implementation of this DNP project will lead to a better understanding and accurate diagnosis of autism for Somali toddlers and their parents. The DNP student concurs that the implementation of the standardized process has a potential impact on the care of Somali toddlers and will benefit the greater Somali community. It will also evoke further projects to promote the health of Somali Children in Minnesota and elsewhere.

Discussion

The results of this quality improvement were revealing. The project team learned that there was no standard workflow for screening toddlers for autism spectrum disorder (ASD), ensuring completion of the MCHAT-R, and documenting the results in the patient electronic

SOMALI TODDLERS AUTISM SCREENING

health record. The PDSA model was applied to facilitate a comprehensive system change to standardize and improve the ASD screening process.

PDSA Cycle One revealed actionable and informative results. The project team found significant discrepancies and a lack of consistent workflow in the completion and documentation of the MCHAT-R for Somali toddlers. The team also discovered that language and cultural barriers were not the cause of poor MCHAT-R completion rates. More than ninety percent of the patients thought questions in the MCHAT-R form were easy to understand, while 95.1% understood and noticed how their child usually behaved, and 92.7% understood and answered questions. The results also showed that 86.8% of patients agreed they understood reasons for completing the MCHAT-R for their child. Moreover, 89.2% of the patients understood the importance of being able to answer the questions to the best of their ability. Finally, 76.3% of patients understood what the health care providers would do with the information.

With these results in mind, the team promulgated a formal clinical guide (Step by step script) to help ensure a consistent, standardized process and a universal message was provided to all patients regarding the completion and documentation of the MCHAT-R in PDSA Cycle Three. In addition to the patient survey, the project team assessed staff practice changes in completion and documentation of the MCHAT-R. Changes in staff practices were evaluated by repeating the initial survey and evaluating the results, after the implementation of the clinical guide.

The post-implementation survey results showed an increase in the completion rate of the MCHAT-R before a patient was called back to the exam room (pre 15.4% versus post 71.4%), indicating that the frontline staff were communicating the importance of completing the MCHAT-R. Additionally, in the post-survey, 20% of staff reported forms were filled out before

SOMALI TODDLERS AUTISM SCREENING

the clinician started the visit compared to 6.7% pre-survey. The post-implementation staff survey also showed a decrease in the amount of time staff needed to clarify questions for patients, from 23% baseline to 6.7% post-survey. The results also showed that there was a decrease in the effort required for staff to explain the form to patients, from a baseline of 46.7% to post implementation of 20%. These results show gains in the completion of the MCHAT-R by Somali families of toddlers, attributed to the implementation of this quality improvement project.

Since the conclusion of this quality improvement project, the quality improvement department made changes within the organization as a direct result of the project. These changes include the implementation of a digital screening form and automatic scoring of the MCHAT-R within the patient's electronic health record. This change eliminates lost or misplaced completed MCHAT-R forms and assures that the results are readily available for staff to review in real time.

The organization also developed a feature whereby the frontline staff can print the MCHAT-R forms with patient labels so interpreters can help families complete the forms if needed. This feature provided an opportunity for patients with language barriers or those who preferred paper forms to complete the MCHAT-R. Additionally, this process decreases the chance of the completed forms getting lost or mislabeled. A nurse is then able to enter the score into the patient's electronic health record, thus ensuring availability of the results in real time. Feedback received from professional medical interpreters concluded that with the clinical guide some technical issues/words are no longer hard to understand or interpret. One interpreter stated that the clinical guide eliminates inconsistencies in the message that the patients receive.

A major finding from this project suggests that of the 20 charts reviewed post-intervention, 95% of 18-month old and 85% of 24-month old MCHAT-R forms were completed and documented in the electronic record. In comparison, prior to the intervention, only 35% of

SOMALI TODDLERS AUTISM SCREENING

the charts reviewed for 18 month olds included MCHAT-R forms, suggesting a 60% increase as a result of this project. For Somali children, aged 24 months, the percentage of charts including a MCHAT-R form increased pre- to post-intervention from 65% to 85%, also demonstrating a significant increase. These findings illustrate the success of the clinical guide to change the MCHAT-R completion and documentation rate within the pediatric department.

Recommendations

In the Somali community, Autism is a new concept. There has been no research to date exploring how the Somali community conceptualizes, understands and experiences Autism. Because of the lack of inquiry and research on this disorder for this population, the Somali community struggles to define what autism is and the reason why the rate of autism is so prevalent. Recommendations for continuing this project include examining the elements of clinical care in regards to autism for Somali children and evaluating whether the development of a culturally congruent screening tool for the Somali children at risk for autism is useful for more sensitive screening.

During the project implementation, the project team identified Somali children with failing MCHAT-R results. However, there was no follow up processes in place. It is important to make sure that there is process for follow up with those patients to assure that they received more extensive evaluation and care. Likewise, the clinic lacks a unified process to track and quantify the impact of early screening on age of diagnosis for autism and related clinical outcomes. It is important to conduct additional quality improvement projects to move this work forward and address these gaps in health services. Partnering with local schools and government programs, such as Help Me Grow, or therapy centers specializing in the diagnosis and treatment of autism, such as Minnesota Autism Center (MAC) or Fraser Center, may improve care coordination and

SOMALI TODDLERS AUTISM SCREENING

support collaborative information sharing and education for all those caring for children with autism spectrum disorders. Lastly, data sharing among agencies can enhance the capabilities of all those involved in the care of children with ASD.

SOMALI TODDLERS AUTISM SCREENING

Reference

- Akhter, L. S., Monkman, J. L., Vang, G., & Pfeiffer, J. (2017). Improving asthma control through asthma action plans: A quality improvement project at a Midwest Community Clinic. *Journal of community health nursing, 34(3), 136-146.*
- American Academy of Pediatrics (AAP) *The AAP Autism Guidelines*. Retrieved from https://www.aap.org/en-us/professional-resources/quality-improvement/Quality-Improvement-Innovation-Networks/Documents/Autism_PreSIP.pdf
- Asarnow, J. R., Jaycox, L. H., Duan, N., LaBorde, A. P., Rea, M. M., Murray, P., ... & Wells, K. B. (2005). Effectiveness of a quality improvement intervention for adolescent depression in primary care clinics: a randomized controlled trial. *Jama, 293(3), 311-319.*
- Baron-Cohen, S., Allen, J., & Gillberg, C. (1992). Can autism be detected at 18 months?: The needle, the haystack, and the CHAT. *The British Journal of Psychiatry, 161(6), 839-843.*
- Boyd, B. A., Odom, S. L., Humphreys, B. P., & Sam, A. M. (2010). Infants and toddlers with autism spectrum disorder: Early identification and early intervention. *Journal of Early Intervention, 32(2), 75-98.*
- Bradshaw, J., Steiner, A. M., Gengoux, G., & Koegel, L. K. (2015). Feasibility and effectiveness of very early intervention for infants at-risk for autism spectrum disorder: A systematic review. *Journal of Autism and Developmental Disorders, 45(3), 778-794.*
- Carakovac, M., Jovanovic, J., Kalanj, M., Rudic, N., Aleksic-Hil, O., Aleksic, B., ... & Pejovic-Milovancevic, M. (2016). Serbian language version of the modified checklist for autism in toddlers, revised, with follow-up: cross-cultural adaptation and assessment of reliability. *Scientific reports, 6, 38222.*

SOMALI TODDLERS AUTISM SCREENING

Campbell, K., Carpenter, K. L., Espinosa, S., Hashemi, J., Qiu, Q., Tepper, M., ... & Dawson, G.

(2017). Use of a digital Modified Checklist for Autism in Toddlers–Revised with follow-up to improve quality of screening for autism. *The Journal of pediatrics*, 183, 133-139.

Carbone, P. S., Norlin, C., & Young, P. C. (2016). Improving early identification and ongoing care of children with autism spectrum disorder. *Pediatrics*, 137(6), e20151850.

Center for Disease Control (CDC).(2014). *Data and Statistics*. Retrieved from

<https://www.cdc.gov/ncbddd/autism/data.html>

Dixon-Woods, M., McNicol, S., & Martin, G. (2012). Ten challenges in improving quality in healthcare: lessons from the Health Foundation's programme evaluations and relevant literature. *BMJ Qual Saf*, bmjqs-2011.

Elder, J. H., Kreider, C. M., Brasher, S. N., & Ansell, M. (2017). Clinical impact of early diagnosis of autism on the prognosis and parent–child relationships. *Psychology research and behavior management*, 10, 283.

Hewitt, A., Gulaid, A., Hamre, K., Esler, A., Punyko, J., Reichle, J. & Reiff, M. (2013).

Minneapolis Somali autism spectrum disorder prevalence project: Community report 2013. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.

Institute for Healthcare Improvement (IHI). (2018). *Plan-Do-Study-Act (PDSA)*. Retrieved from

<https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlit toolkit2-tool2b.html>

Dang, D., & Dearholt, S. (2017). *Johns Hopkins nursing evidence-based practice: model and guidelines*. 3rd ed. Indianapolis, IN: Sigma Theta Tau International.

SOMALI TODDLERS AUTISM SCREENING

Minnesota Department of Health [MDH]. (2014). A Qualitative Study of Families of Children with Autism in the Somali Community: Comparing the Experiences of Immigrant

Groups. Retrieved from: <http://www.leg.state.mn.us/lrl/lrl.asp>

Morelli, D. L., Pati, S., Butler, A., Blum, N. J., Gerdes, M., Pinto-Martin, J., & Guevara, J. P.

(2014). Challenges to implementation of developmental screening in urban primary care: a mixed methods study. *BMC Pediatrics*, *14*(1), 16.

Robins, D. L., Casagrande, K., Barton, M., Chen, C. M. A., Dumont-Mathieu, T., & Fein, D.

(2014). Validation of the modified checklist for autism in toddlers, revised with follow-up (M-CHAT-R/F) . *Pediatrics*, *133*(1), 37-45.

Scarpa, A., Reyes, N. M., Patriquin, M. A., Lorenzi, J., Hassenfeldt, T. A., Desai, V. J., &

Kerkering, K. W. (2013). The modified checklist for autism in toddlers: Reliability in a diverse rural American sample. *Journal of Autism and Developmental Disorders*, *43*(10), 2269-2279.

Varkey, P., Reller, M. K., & Resar, R. K. (2007). Basics of quality improvement in health care. *Mayo Clinic Proceedings (Vol. 82, No. 6, pp. 735-739)*. Elsevier.

Walsh, J. M., McDonald, K. M., Shojanian, K. G., Sundaram, V., Nayak, S., Lewis, R., ... &

Goldstein, M. K. (2006). Quality improvement strategies for hypertension management: a systematic review. *Medical care*, 646-657.

SOMALI TODDLERS AUTISM SCREENING

Appendix A

Modified Checklist for Autism in Toddlers (M-CHAT)

Please fill out the following about how your child usually is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.		
1.	Does your child enjoy being swung, bounced on your knee, etc.?	Yes No
2.	Does your child take an interest in other children?	Yes No
3.	Does your child like climbing on things, such as up stairs?	Yes No
4.	Does your child enjoy playing peek-a-boo/hide-and-seek?	Yes No
5.	Does your child ever pretend, for example, to talk on the phone or take care of dolls, or pretend other things?	Yes No
6.	Does your child ever use his/her finger to point, to ask for something?	Yes No
7.	Does your child ever use his/her finger to point, to indicate interest in something?	Yes No
8.	Can your child play properly with small toys (e.g., cars or bricks) without just mouthing, fiddling, or dropping them?	Yes No
9.	Does your child ever bring objects over to you (parent) to show you something?	Yes No
10.	Does your child look you in the eye for more than a second or two?	Yes No
11.	Does your child ever seem oversensitive to noise? (e.g., plugging ears)	Yes No
12.	Does your child smile in response to your face or your smile?	Yes No
13.	Does your child imitate you? (e.g., you make a face-will your child imitate it?)	Yes No
14.	Does your child respond to his/her name when you call?	Yes No
15.	If you point at a toy across the room, does your child look at it?	Yes No
16.	Does your child walk?	Yes No
17.	Does your child look at things you are looking at?	Yes No
18.	Does your child make unusual finger movements near his/her face?	Yes No
19.	Does your child try to attract your attention to his/her own activity?	Yes No
20.	Have you ever wondered if your child is deaf?	Yes No
21.	Does your child understand what people say?	Yes No
22.	Does your child sometimes stare at nothing or wander with no purpose?	Yes No
23.	Does your child look at your face to check your reaction when faced with something unfamiliar?	Yes No