THE DEVELOPMENT OF A STRUCTURED, SYSTEMATIC AND STANDARDIZED PRACTICE GUIDELINE FOR REGISTERED NURSES CARING FOR AUTISTIC CHILDREN UNDERGOING DAY SURGERY

by © Samantha Glover

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Abstract

Background and Purpose: There is an alarmingly high prevalence and incidence of Autism Spectrum Disorder among children in Canada, with the highest percentage of new diagnosis occurring in Newfoundland and Labrador. Despite evidence supporting the need, there are no nursing practice guidelines currently available for perioperative Registered Nurses (RNs) at the Janeway Children's Hospital caring for autistic children undergoing day surgery. The purpose of this practicum was to develop and appraise a nursing practice guideline for RNs to assist them when caring for autistic children undergoing day surgery. **Methods:** First, an integrative literature review was conducted to critique current research on best practice nursing guidelines for the care of autistic children undergoing day surgery, examine the gaps in the literature surrounding existing nursing practice guidelines and explore strategies to address the nursing care needs of this population. Second, consultations with key stakeholders were completed to investigate current nursing practice guidelines, and suggestions for future guideline development. Lastly, an environmental scan was conducted to identify and evaluate current guidelines for the care of autistic children undergoing day surgery. **Results:** Guidelines for perioperative nursing care for this population were developed that included three practice recommendations: continuity of care, environmental modifications, and procedural modifications. **Conclusion**: Implementation and evaluation of these Guidelines could help to improve the delivery and quality of nursing care and could lead to improved perioperative experiences for autistic children and their families undergoing day surgery.

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Table of Contents

List of Appendices

Introduction

There is an increasingly high prevalence of children receiving a diagnosis of Autism Spectrum Disorder (ASD) in Canada, and particularly in the province of Newfoundland and Labrador (NL). According to a 2018 report published by the Public Health Agency of Canada (PHAC), approximately 1 in 66 children are diagnosed with ASD in Canada. In NL there is a higher prevalence of ASD as compared to all other provinces and territories of Canada with a 1 in 57 children diagnosed with ASD in 2015 (PHAC, 2018). This high prevalence compounded by the comorbidities associated with ASD, result in children having more frequent encounters with primary health care, specialty care, and acute care than those children without ASD (Cummings et al., 2016). The perioperative setting is a particularly distressing environment for autistic children given the disruption of daily routines, unfamiliar environment and staff, excessive noise, and ample external stimuli (Nelson & Amplo, 2009).

Caring for autistic children during the perioperative period can be challenging for perioperative nurses, and it is recommended that nurses take an innovative, evidenced based approach to care (Bultas, 2012). The purpose of this practicum was to develop a structured, systematic, and standardized nursing practice guideline for RNs caring for autistic children undergoing day surgery, hereinafter called the "Guideline". It is anticipated the Guideline could improve the delivery, and quality of care being provided to autistic children and their families during the perioperative period. In turn, the implementation and evaluation of the Guideline will lead to improved perioperative experiences for autistic children and their families.

Purpose and Objectives

The overall goal for this practicum was to develop and appraise a nursing practice guideline for RNs to assist them when caring for the autistic child and their families undergoing day surgery. The key practicum objectives were:

1) Demonstrate the advanced nursing practice competencies of direct comprehensive care, optimizing the health system, research utilization, leadership and consultation and collaboration.
2) Develop a nursing practice guideline to guide decision-making of registered nurses caring for autistic children undergoing day surgery at the Janeway pre admission clinic.
3) Conduct a comprehensive literature review to identify best practice guidelines that have had positive effects on the behaviors of autistic children undergoing day surgery.
4) Conduct consultations with key informants to explore current best practice guidelines for autistic children undergoing day surgery.
5) Conduct an environmental scan of preadmission clinics to explore current best practice guidelines for autistic children undergoing day surgery.

Overview of Methods

An integrative literature review was conducted to assess what is known about the topic of caring for autistic children undergoing day surgery, to identify evidence to justify the need for the development of a nursing practice guideline and to identify current best practice for this population. The literature review was completed in three drafts with each draft further reviewed and critiqued, and necessary changes made under the guidance of an appointed supervisor (Appendix A). Following the completion of the literature review, consultations were

conducted with key informants using a questionnaire containing a series of open-ended questions. The questionnaires were administered to the key informants via email or face to face interviews. Results of the questionnaires were analyzed and major themes identified amongst the responses of the consultants. A consultation report was then completed through three drafts, with each draft being reviewed by an appointed supervisor with the necessary changes made until the final draft was deemed satisfactory (Appendix B).

The next investigatory step involved an environmental scan. This scan consisted of a review of current provincial perioperative nursing practice guidelines and programs for specificity and applicability to children with ASD undergoing day surgery. The results of the environmental scan lead to the development of an environmental scan report, which was completed in three drafts with each draft receiving review by an appointed supervisor and necessary changes made until the final draft was deemed satisfactory (Appendix C).

Summary of Literature Review

The literature review confirmed the need to develop practice guidelines for perioperative RNs caring for this population and although limited research was available, there was adequate evidence to develop the content of the guideline. Key results identified by the integrative review of the literature included the alarmingly high prevalence and incidence of ASD amongst children in Canada, with the highest percentage of children with a new diagnosis of ASD residing in Newfoundland and Labrador. It was also clear that children with ASD are more likely to have frequent visits to the hospital given the comorbidities and complex medical management associated with their diagnosis (Benich et al., 2018). However, there are challenges associated with caring for autistic children undergoing day surgery including

maladaptive behaviors and negative responses to nursing care immediately prior to surgery (Gearner-Thompson & Tielsch-Goddard, 2013). Given the social, communication, sensory, and executive functioning difficulties experienced by autistic children, and the unpredictable disruption in routine, overwhelming external stimuli, and unfamiliarity of staff of the day surgery unit, the perioperative experience can be distressing for autistic children. The literature review confirmed that children diagnosed with ASD can have difficulty coping and complying with the perioperative nursing care required to prepare them for day surgery.

The literature review helped to identify several main themes that were taken into consideration when developing the practice guideline for perioperative RNs caring for autistic children undergoing day surgery. These themes include; greater parental involvement, the need for an individualized plan of care, maintenance of continuity and familiarity of staff, incorporation of visual learning strategies, and the need to modify the perioperative environments. Refer to Appendix B for the complete literature review and literature summary table utilized during the development of this practicum project. The following is a brief discussion of the main themes arising from the literature review.

Greater parental Involvement refers to acknowledging that the parents of the child are the experts in their care, and consulting with them to gather information about how best to interact with their child. Involving the parents or guardians in individualizing a plan of care can improve the quality of perioperative nursing care received by the child and their families (Benich et al., 2018). Individualized plans of care are important, as they serve as a way for all members of the healthcare team to be aware of the different needs of each child. Individualized plans of care are an effective method of providing care to autistic children,

especially when those plans included information provided by parents (Gearner Thompson and Tielsch-Goddard, 2013).

Continuity and familiarity of the perioperative staff will allow for a more positive experience for both the child and the parents. Lindberg, von Post, and Eriksson (2012) found that consistency in staff led to improved perioperative dialogues between nurses and families and eased distress for both parents and children. Another strategy to enhance the quality of nursing care is to incorporate learning strategies that include visual aids. Using visual aids is an effective method of communicating with autistic children who may have difficulties communicating verbally. It is imperative that nurses be aware of the communication style of preference for the child, and adjust their nursing care accordingly. Nelson and Amplo (2009) suggest that children on the autism spectrum may also require alternative methods of communication, such as breaking the perioperative process into individual steps that are supplemented with simple visual aids.

There is a need to modify the perioperative environment for autistic children because the busy, fast paced environment it is difficult for autistic children to adapt. Drake et al. (2012) found that the use of a "coping kit" could ease the distress and refocus the autistic child's mind and help them to have a positive response to nursing care immediately prior to surgery (i.e., distractive toys, activity sheets). Research also shows that it is necessary to modify the perioperative environmental and procedures when caring for autistic children. Environmental and procedural modifications should be a reflection of the information received from the parents and the nonverbal cues of the child. The evidence within the literature review supports

the need for the development a nursing practice guideline that encourages an individualized plan of care with modification of the environment and procedures.

Through the completion of the integrative literature review, the "Appraisal of Guidelines for Research and Evaluation for Health Systems" (AGREE-HS Research Team, 2018; AGREE Enterprise, 2017) was identified as an appropriate tool to guide the development of the Guideline as well as appraise the quality and appropriateness of the guideline once it has been developed (Appendix D). As well, the Iowa Model (White & Spruce, 2015) was used as the theoretical framework for the development of this nursing practice guideline and to develop the implementation and evaluation plan for the guideline.

Summary of Consultations

All consultants supported the development of evidenced based practice guidelines for perioperative RNs caring for autistic children undergoing day surgery. The main themes arising from the consultations with perioperative pre-admission RNs, nurse managers and pediatric anesthesiologists included: the need for nurses to be familiar with the features and characteristics of ASD; the need to tailor nursing practice guidelines to meet the unique needs of this population, and the need to maintain clear lines of communication amongst all healthcare team members involved in the child's care on the day of surgery. As well, all participants reported that there is great value in consulting with the parents of autistic children prior to the development of a plan of care. Refer to Appendix C for a complete report of the data collected through consultations.

Unfortunately, all consultants identified either an absence of practice guidelines or insufficient practice guidelines to guide nursing practice when caring for this population.

Perioperative RNs outside of NL identified that practice guidelines are available and utilized those to provide training for healthcare personnel to better understand ASD and how to tailor their practice to meet the needs of this population. However, those practice guidelines are not available outside of the organization. Recommendations from key informants included developing a nursing practice guideline that is standardized yet versatile enough to allow for individualized plans of care for each autistic child preparing for day surgery.

Summary of Environmental Scan

The environmental scan yielded key results that supported the development of nursing practice guidelines for perioperative RNs caring for autistic children undergoing day surgery. Based on the review of the websites of governing associations of Registered Nurses in Newfoundland and Labrador, Nova Scotia and PeriAnesthesia Registered Nurses of Canada, it was evident that there were no nursing practice guidelines and standards with exclusive language suggestive of caring for an autistic child undergoing day surgery. While there were general practice guidelines that could be applied to this population, such as conducting comprehensive nursing assessments, developing individualized plans of care, providing holistic care, and practicing inter-professional collaboration, there were no specific references to practice guidelines for RNs caring for this population.

Only one program was identified in the environmental scan that could be applied to guidelines for caring for this population, the Building Alliances for Autism Needs in Clinical Encounters (BALANCE) program that was developed and is being implemented at Atlantic Canada (BALANCE, 2019). An evaluation of the BALANCE program is available on the program's website, suggests that the program is highly sustainable and effective as evidenced by high

ratings from staff members who have undergone the training modules and utilized the program in practice. Unfortunately, this program is not available outside of the organization. The findings of this environmental scan provided justification of the need to develop structured, systematic, and standardized nursing practice guidelines for perioperative RNs caring for autistic children undergoing day surgery. Refer to Appendix D for the complete report of the data collected during the environmental scan.

Guidelines for the Nursing Care of Autistic Children

The purpose of this Guideline is to provide RNs with evidence-based recommendations of foundational surgical day care for children with a diagnosis of autism spectrum disorder (ASD), with the intent to guide and improve the practices of the perioperative RN. The scope of the Guideline developed for this practicum project includes effective assessment and management of the autistic child throughout each step of the perioperative process including: check in; assessment; preoperative care; entering the operating room; post op care and preparing for discharge home. The Guideline is inclusive of nursing practice recommendations based on the results of an integrative review of the literature, consultations with key stakeholders and an environmental scan. The Guideline is divided into three major themes with practice recommendations falling within each of these themes. The following is a brief discussion of the major themes of the Guideline including: (1) continuity of care, (2) environmental modifications, and (3) procedural modifications. Refer to Appendix A for a complete copy of the Guideline.

Continuity and Familiarity of Care

Continuity of care refers to appreciating the value of parental expertise and suggests that perioperative RNs utilize the information provided by the parents / guardians to modify their practice to meet the needs of the child. Consulting with the parents can help RNs to identify the child's preferred communication techniques, recognize behavioral signs of distress, identify sensory preferences and collect other important information specific to the child that can be used to individualize care (Gearner Thompson & Tielsch-Goddard, 2013; Nelson & Amplo, 2009). The Guideline recommends using "My Perioperative Passport" as one approach to help RNs individualize the plan of care for each child. The information collected in the passport can be used to support the child's care as they pass through the different phases of day surgery from admission to recovery. The passport collects information from the parents that can aid in the delivery of effective, individualized nursing care and create a positive perioperative experience for both the child and the parent.

Familiarity with the staff of the day surgery unit can help to alleviate distress for children and all those involved. In an effort to create familiarity, evidence supports one RN being assigned to the child throughout the perioperative process. Perioperative dialogues between RNs, children and their families were well established when a familiar face followed them throughout the perioperative process. Having a perioperative RN who is familiar to both the child and parent/guardian, can reduce anxiety and improve cooperation (Lindberg, von Post, & Eriksson, 2012). Creating a comforting perioperative environment for the child stems from limiting the number of new healthcare personnel the child encounters during their visit (Benich et al., 2018). Consulting with parents to ensure continuity of care and being familiar

with the perioperative RNs staff during the perioperative period can reduce anxiety and improve cooperative behaviors in the autistic child.

Environmental Modifications

The day surgery department is incredibly fast paced, busy, noisy, and can lead to autistic children feeling overwhelmed and experiencing stimulus overload. Nelson and Amplo (2009) and Short and Calder (2013), suggests that autistic children be separated from the chaos of the day surgery department to a room where they are exposed to limited auditory stimuli and greater amounts of visual stimuli. These environmental modifications can help autistic children to keep their minds busy, so that their focus will be diverted away from the perioperative processes that they are about to experience.

A designated room or space for autistic children is warranted to reduce the stress associated with the perioperative environment. As well, autistic children should be slowly introduced to one piece of medical equipment at a time over several minutes e.g. the stethoscope, the blood pressure cuff, and finally the thermometer. Approaching the child with several pieces of equipment at the same time, that require excessive tactile stimulus can be very distressing and cause them to feel overwhelmed. In an effort to provide more visual stimuli to help distract the autistic child during care, RNs are encouraged to implement a "Coping Kit" upon arrival to the day surgery department.

A "Coping Kit" includes items or toys that are used as distractors for autistic children leading up to their day surgery procedure. They could be personal toys the child brings from. home. The items are placed in a clear bag, given to each child upon registration at the day surgery department, and returned to the parents or front desk prior to discharge. If items are

provided by the agency they should disposable or disinfected as per agency policy following each use. The contents of the coping kit could include such items as: a. personal toy, a stretchy resistant band; a plastic kaleidoscope; Rubik's Cube; stress ball; activity sheets, jig saw puzzles, coloring books, washable markers or crayons. The items are intended to be used at the child's discretion as often or as little as they would like during their time at the perioperative department. The RN assigned to care for the child should encourage both the child and the family members to engage in the activities in the Coping Kit if provided.

Procedural Modifications

Procedural modifications include changes to the usual day surgery procedures that can help children adapt to the perioperative processes. The literature suggests and key informants agree, that the rules and regulations surrounding the perioperative department should be flexible enough to best meet the individual needs of autistic children. Positive perioperative experiences have been linked to procedural modifications such as introducing strategies to reduce wait times, and subsequently fasting times. These procedural modifications have been shown to result in children experiencing less disruption in their normal routines which have been linked to more positive perioperative experiences (Benich et al., 2018; Delaney et al., 2015).

Effective perioperative planning involves organizing the day surgery list in such a way as to accommodate the needs of autistic children, including speeding them through the process as quickly and safely as possible (Gearner Thompson and Tielsch- Goddard, 2013; Nelson and Amplo, 2009). As well, allowing parental presence throughout each step of the perioperative process has been suggested by key stakeholders, as necessary to alleviate the distress

experienced by the child. These procedural modifications are simple small steps that can have a major impact on the perioperative experience for autistic children and their families.

Another procedural modification that can be made to the day surgery procedure includes using visual aids to educate the child and family. Visual aids such as a check list with reward stickers for successfully completing each step of the perioperative process provides the child with a focus and a definitive end to the process. Research confirms that children with autism respond best to visual aids. Such methods have led to improved behaviors, increased cooperation, and reduced anxiety related to the perioperative process. The visualization tool developed for this project "My Surgery Day!" is a rather simple solution to an otherwise distressing situation. The tool provides a visual check list with reward stickers to show the successful completion of each step of the process. The child receives the completed check list to take home upon discharge. Research shows that visual symbols or tools are not only an efficient communication tool in the perioperative setting, but are also a highly feasible and cost-effective method that could be utilized regularly by nurses in any day surgery department (Vaz, 2013).

Development and Appraisal of the Guideline

The Appraisal of Guidelines for Research and Evaluation Instrument (AGREE II) was used to develop and appraise the Guideline developed for this practicum. AGREE II provides a structured, systematic and standardized methodological framework for developing a practice guideline and assessing the quality of that guideline. Following the AGREE II framework helped to create a structured Guideline with specific items including: (1) the health topic or challenge, (2) participants, (3) methods, (4) recommendations, and (5) implementation. The Guideline was

further standardized by identifying specific criteria for each item e.g. the health challenge was the nursing care of autistic children and their families undergoing day surgery.

The AGREE II is also designed to appraise practice guidelines and assist the appraiser with determining the rigor and transparency of the guideline. The AGREE II not only provided a standard methodological process for appraising the Guideline developed for this practicum, it also helped to assess the quality of the guideline and how information should be presented. The AGREE II considers twenty-three questions under six domains that are rated using a 7-point scale with seven being the highest quality rating. Based on the overall ratings and quality of the guideline, the guideline will either be recommended for use or for revision. The AGREE II was used by the author to appraise the Guideline and the on line assessment report is presented in Appendix E. Based on the AGREE-II appraisal, the Guidelines was recommended for practice, but it is recognized that the Guideline would require agency approval and the development of a detailed implementation and evaluation plan. That plan would include key informants conducting their own appraisals of the Guideline using the AGREE-II tool. The following is a brief discussion of the findings from this Author's appraisal report of the Guideline.

Scope, Purpose and Target Population

The first domain of the AGREE II examines information pertaining to the scope, purpose, and target population. The Guideline rated high in this domain with a score of 16 out of a possible 21 points. The objectives and the health question answered by these guidelines are specifically described and easily identified. As well, the target population is clearly defined as the perioperative RNs.

Stakeholder Involvement

The second domain of the AGREE II considers stakeholder involvement during the development of the guideline. The ratings within this domain reflect identification of the key stakeholders and the representation of their views within the development of the guideline. The Guideline rate high in this domain with 19 out of a possible 21 points. This would indicate that key stakeholders did influence the development of the Guideline and the content of the Guide incorporated information from consultations with key stakeholders.

Rigor of Development

The third domain of appraisal refers to the rigor of the development of the guideline. In other words, this domain considers how the evidence that supported and led to the development of the guideline was collected and synthesized, as well as the methodology used to formulate recommendations. The Guideline was rated as moderately well on the scale (i.e., 39 out of a possible 56 points). This would indicate that the methodologies for data collection in the literature review, environmental scan and consultations were systematic and clearly described.

Clarity of Presentation

The fourth domain of AGREE II considers the clarity of presentation of the guideline. This particular domain focuses on the language, structure, and formatting of the guideline when it is presented to an audience. The guidelines within the learning module score high in this domain (i.e., 19 out of a possible 21 points). The language used in the recommendations presented in the Guideline is clear and easily recognized by the audience. The formatting of the Guideline followed APA format as well as included the content recommendation by AGREE II.

Applicability

The fifth domain of this instrument refers to applicability of the guideline. This domain refers to how well the barriers and facilitators to implementation of the guideline are identified and described. The guidelines in the learning module rate moderately well in this domain (i.e., 19 out of a possible 28 points). While the facilitators and barriers to the guidelines have been identified, there is no mention of monitoring or auditing criteria at present.

Editorial Independence

The sixth domain of the AGREE II instrument refers to editorial independence, that is, consideration of competing views of interest of funding bodies. This domain does not apply to the Guideline at this time, because there were no funding bodies and only the author and supervisor were involved in the development of the Guideline, therefore the rating for this domain is low (i.e., 2 out of a possible 14 points). This domain score will change once the organization reviews and approves the Guideline for practice.

Overall Quality

The overall quality of the Guideline was determined to be five out of seven, given the high ratings in the majority of the domains listed above. A rating of 5 indicates that not all criteria have been met, primarily related to the need for the Guideline to be reviewed and evaluated by the organization. This limitation will be addressed further in the plan for implementation and evaluation of the Guide. Based on the domain assessment ratings and the quality assessment rating, it can be concluded that the Guideline could be recommended for use once appraised and approved by the organization. A full discussion of the findings for the author's appraisal of the guideline is presented in to Appendix E.

Advanced Practice Competencies

The following is a discussion of the advanced practice competencies achieved during this practicum including: direct comprehensive care, optimizing the health system, education, research utilization, leadership, consultation and collaboration, continuing competence (CNA, 2019).

Direct Comprehensive Care

According to the Canadian Nurses Association (2019), direct comprehensive care involves taking a holistic approach to a specialized area of nursing. The completion of this practicum has allowed me to demonstrate my ability to integrate nursing theory, research, grey literature, and personal nursing knowledge through the development of an integrative literature review, an environmental scan report, and a consultation report. The completion of the activities and reports involved in the development of this practicum have enabled me to identify, plan, and assess the trends and patterns of data that contribute to the development of learning resources inclusive of nursing practice guidelines. The development of this Guideline has allowed me to identify and analyze the complex interactions between determinants of health and the lived experiences of autistic children undergoing day surgery and their families. These same advanced practice nursing skills contribute to the appraisal of the proposed nursing practice guidelines using the AGREE II instrument.

Optimizing Health System

The optimizing health system competency proposed by the Canadian Nurses Association (2019) has been demonstrated through the completion of this practicum project. I have consulted and collaborated with various health-care professionals throughout the development

of the Guideline, as well as the appraisal and evaluation of the Guideline. The completion of the literature review and environmental scan allowed me to not only identify gaps in access to guidelines for perioperative nursing practicing in Newfoundland and Labrador, but also within Canada. The Guideline developed for this practicum project proposes strategies that could fill those gaps by providing access to current, high quality guidelines for RNs caring for autistic children and their families undergoing day surgery.

Education

The Canadian Nurses Association (2019) proposes that advanced practicing nurses be committed to professional growth and learning, and encouraging those same attributes in our patient population. This practicum has allowed me to develop and plan for implementation of a practice Guideline that will serve as a learning resource for perioperative nurses and autistic children and their families. The development of the Guideline has increased my professional knowledge and growth since the early phases of the practicum courses, and that learning has continued as I seek feedback and evaluation of the Guideline from the organization. As well, presenting the Guideline to the organization will contribute to the knowledge and growth of the perioperative RNs caring for autistic children.

Research Utilization

The Canadian Nurses Association (2019) proposes that advanced practice nursing should involve not only the identification of research but the utilization of that research to improve practice. The development of this practicum project has allowed me to demonstrate my ability to appraise, synthesize, apply, and disseminate current research as evidenced by the completion of an integrative literature review and an environmental scan. As well,

consultations with identified key informants has allowed me to conduct qualitative research, manage, and analyze the findings into a consultation report. The utilization of the research conducted and identified within this practicum has aided in the development and appraisal of nursing practice guidelines that are designed to enhance perioperative nursing practice with autistic children. These research skills will be carried through and strengthened throughout the further dissemination of the Guideline.

Leadership

The advanced practice nursing competency of leadership involves not only assuming the role of a leader, but also acting as a change agent in practice (Canadian Nurses Association, 2019). I have demonstrated the role of both a leader and a change agent through my discussions with consultants regarding the purpose of the proposed practicum, and explaining how their opinions would be of benefit to the development of a nursing practice guideline. The overall practicum project has allowed me to serve as an advocate for change to improve and optimize the current perioperative nursing care being received by autistic children and their families undergoing day surgery.

Consultation and Collaboration

The advanced practice nursing competency of consultation and collaboration involves the demonstration of effective communication amongst healthcare professionals for the betterment of the patient (Canadian Nurses Association, 2019). The activities and reports completed during this practicum have allowed me to consult and collaborate with healthcare professionals to better the care of autistic children and their families by gaining information that has supported the development of the Guideline. Effective consultation and collaboration

with key stakeholders, served as an important component in the development of the Guideline to improve the outcomes and experience of autistic children and their families undergoing day surgery at the Janeway.

Continuing Competence

All advanced practice nurses are required to maintain their competence through participating in educational and professional development (CNA, 2019). The completion of this this practicum has allowed me to continue to expand my knowledge, learning, and development through completing literature reviews, conducting environmental scans, and key stakeholder consultations on the needs of this population. As well, developing the Guideline has enhanced my understanding of the nursing care needs of this population and improved my competence as a perioperative nurse to care for autistic children undergoing day surgery.

Implementation Plan for the Guide

Once the Guideline has been approved by the organization, the Divisional Manager in collaboration with the Nurse Educator could deliver key messages from the Guideline by providing copies of the Guideline, including copies of the "My Sticker Day Chart" and "My Perioperative Passport" on the unit and conducting four 15-minute information sessions with all RNs (two sessions on each side of the shift). During those sessions the Nurse Educator will briefly present the evidence used to develop the Guideline and the recommendations arising from the Guideline. A demonstration of how to utilize the components of the Guideline in everyday nursing practice will be presented. Keeping attendance records of the sessions will ensure all RNs received the information. At the end of the information sessions the RNs will have the opportunity to provide feedback on the Guideline.

Future recommendations for the implementation of the Guide would include a presentation to a wider audience of key stakeholders via PowerPoint, during an education conference or a lunch an learn opportunity. The presentation will be most effective if presented at an education conference such as the Eastern Health Nursing Education and Research Council Annual Research Symposium where the audience will consist of RNs with various nursing experience, who could potentially utilize components of the Guideline within their own practice. As well, presenting to other members of the health care team at the Janeway perioperative department through a lunch and learn, would be an effective option to promote and reinforce the for practice arising from the Guideline.

Evaluation Plan for the Guide

While this Guideline is seemingly cost effective and feasible for implementation in a pediatric day surgery department; further planning, implementation and evaluation will require approval from the appropriate health care authority. It is recommended that an evaluation plan be put into place based on the Iowa Model of Evidenced- Based Practice. It is recommended that a key stakeholder team be established to review and appraise the Guideline. The team could consist of nurse managers, patient care facilitators, anesthesiologists, surgeons and RNs. The team would review the proposed Guideline, evaluate the feasibility for implementation, and appraise the quality of the Guideline utilizing the AGREE II Instrument. Based on the rating determined by the team, the team members will then discuss recommendations for revising and or piloting the Guideline for practice. A focus group with the perioperative RNs approximately one month post the pilot would be beneficial to evaluate the Guideline and make recommendations for improvements of the Guideline going forward.

Conclusion

This practicum project demonstrated Advanced Nursing practice competencies through applying the process of the AGREE II framework to the development and appraisal of a nursing practice guideline for RNs caring for autistic children undergoing day surgery. The activities of the project included consultations with key stake holders, a scan of the environment, and an integrative review of the literature. A critical appraisal and quality evaluation of the Guideline was conducted using the AGREE II instrument and the Guideline was recommended for use with this population. However, the Guideline must be reviewed and approved by the organization prior to use in practice. Implementation and evaluation of the recommendations arising from the Guideline developed for this practicum project, could help to improve the delivery and quality of nursing care and could lead to improved perioperative experiences for autistic children and their families undergoing day surgery.

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Appendix A. Guidelines for the Care of Autistic Children Undergoing Day Surgery

GUIDELINES FOR THE CARE OF AUTISTIC CHILDREN UNDERGOING DAY SURGERY

Faculty of Nursing
Memorial University of Newfoundland

Table of Contents

How to Use This Document

This Guideline is designed to help perioperative Registered Nurses (RNs) as they address the unique needs of autistic children undergoing day surgery. Given the social, communication, sensory, and executive functioning of autistic children, and the unpredictable disruption in routine, overwhelming external stimuli, and unfamiliarity of staff, undergoing day surgery can present complex challenges for patients, families and care givers. This Guideline can be used as a resource when planning individualized care to meet the unique needs of this population. RNs will benefit from reviewing the recommendations and the evidence in support of the recommendations.

Purpose and Scope

The purpose of this Guideline is to provide RNs with **evidence-based recommendations of foundational surgical day care for children with a diagnosis of autism spectrum disorder (ASD), with the intent to guide and improve the practices of the perioperative RN.** The scope of this Guideline includes effective assessment and management of children diagnosed with ASD undergoing day surgery throughout each step of the perioperative process.

This Guideline answers the specific health question: How does a perioperative RN meet the individualized needs of a child diagnosed with ASD undergoing day surgery? This Guideline has been developed with the aim to improve the delivery and quality of care being provided to autistic children and their families during the perioperative period. Recommendations in this Guideline will provide perioperative RNs with direction in providing optimal nursing care, and improving experiences for autistic children and their families undergoing day surgery.

Search Strategies

Various qualitative and quantitative research articles and grey literature were compiled using several search engines including CINHAL, PubMed, Science Direct, and Google Scholar. Literature was not limited to publication year or country, given the limited amount of research conducted on this topic. Publication dates ranged from 2009 and 2019. Search terms used included CINHAL headings “perioperative nursing” AND “autism spectrum disorder”, “children” AND “autism spectrum disorder”, “perioperative management” AND “autism spectrum disorder”, and “nursing practice guidelines”. PubMed MESH terms included “ASD”, “pediatric perioperative nursing”, “autism spectrum disorder”, and “perioperative care”.

Literature was selected based on the ability to address the purpose and target population of the Guideline. Research was inclusive of children aged 0 to 16, and was not limited based on gender. Research studies that involved children with a developmental disability other than ASD, were also included. Literature was limited to the English language and to nursing and pediatric day surgery given the purpose of the review. The wide age range and varying stages and characteristics of development disability may impact the generalizability of results.

Background Context

What is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a lifelong developmental disability which varies in degree of severity and affects communication patterns, behavior, social interaction, response to stimuli, and intellectual ability. The earlier ASD is identified, the earlier management and treatment plans can be put into place, thus leading to improved quality of life. Children with ASD often have frequent encounters with the health care system, therefore, it is important for RNs to be familiar with how the variation in characteristics of ASD can present and how to care for children who are on all levels of the spectrum (Autism Society, 2019). The criteria for ASD includes:

> "*stereotyped or repetitive motor movements; inflexible adherence to routines; highly restricted, fixated interests that are abnormal in intensity or focus; and hyper- or hypo activity to sensory input or unusual interests in sensory aspects of the environment"* (American Psychiatric Association, 2013, p. 50-51).

ASD affects the functioning and processing mechanisms within the brain (Short & Calder, 2013). While there is no cure for ASD, there are alternative treatments and medications that can help manage the signs and symptoms of ASD (Nelson & Amplo, 2009). Given the diversity of a diagnosis, it can be said that no two children with autism are alike and therefore, no two treatment plans should be alike (Koski, Gabriels, & Beresford, 2016).

What is Perioperative Nursing?

Perioperative nursing is a specialized area of nursing which requires the Registered Nurse to have a high quality knowledge base that supports positive patient outcomes preoperatively. The nurse must assume the role of clinician, educator, advocate, and researcher while keeping the best interests of the patient at the centre of care (AORN, 2015). Perioperative nursing occurs in ambulatory surgery centers and according to the Association of Registered Nurses of Newfoundland and Labrador (2015), the goal of perioperative nursing practice is to provide holistic care and support to patients and their families, in an effort to assist them in achieving optimal wellness before and after their surgical procedure. Perioperative Registered Nurses must engage in interdisciplinary collaboration and the utilization of available resources in order to provide well rounded care to all patients during their surgical preparation (AORN, 2015).

Caring for Autistic Children Undergoing Day Surgery

Children with ASD are more likely to have frequent visits to the hospital given the comorbidities and complex medical management associated with their diagnosis (Benich et al., 2018). Characteristics associated with a diagnosis of ASD can impact on a child's ability to adapt to the perioperative process especially immediately prior to day surgery (Gearner-Thompson &

Tielsch-Goddard, 2013). The social, communication, sensory, and executive functioning challenges experienced by autistic children and the unpredictable disruption in routine, along with the overwhelming stimuli and unfamiliarity of staff of the day surgery unit can all impact on the child's reaction to perioperative nursing care. When planning care for this population it is important to consider parental involvement, continuity and familiarity of staff, visual teaching aids and modifications to the perioperative environment.

Parental Involvement. Acknowledging the parents of the child as being the experts in their care, and consulting them to gather information about how best to interact with their child, can improve the perioperative experience for the child and parent (Benich et al., 2018; Gearner Thompson and Tielsch-Goddard, 2013). Consulting with the parents or guardians can lead to identification of preferred communication techniques, behavioural signs of distress, sensory preferences, and other important information specific to the child (Gearner Thompson & Tielsch-Goddard, 2013; Nelson & Amplo, 2009). An individualized plan of care can then stem from that information and aid in the delivery of a positive perioperative experience.

Individualized Plan of Care. It is important for all members of the healthcare team to be aware of the individual needs of the autistic child. Individualized plans are an effective method of providing care to children with ASD, especially when those plans include information from parents (Gearner Thompson and Tielsch-Goddard, 2013). Current research supports the development of an individualized plan of care that is formulated in collaboration with the parents or guardians and is developed prior to the commencement of the perioperative process (Benich et al., 2018; Gearner-Thompson & Tielsch-Goddard, 2013; Koski, Gabriels, & Beresford, 2016; Lindberg, von Post, & Eriksson, 2012).

Continuity and Familiarity of Staff. Parents report feeling helpless, hopeless, and suffering in silence when there aren't consistent health care personnel involved in the perioperative care of their autistic child (Lindberg, von Post, and Eriksson, 2012). The thought of encountering staff who lacked an understanding of the uniqueness of their child brought upon feelings of distress in parents. Conversely, when perioperative dialogues were well established and one familiar face followed parents throughout the perioperative process, feelings of hopelessness and suffering were alleviated. Having a nurse whom the child and parent recognize can help to ease anxiety and improve the cooperation and behaviors of the child during the perioperative process (Lindberg, von Post, & Eriksson, 2012). Overall, continuity and familiarity of perioperative staff allowed for a more positive experience for both the child and the parents. Benich et al. (2018) also suggest that creating a comforting perioperative environment for the child stems from limiting the number of new healthcare personnel the child encounters during their visit.

Visual Teaching Aids. Difficulties communicating and comprehending commands is a characteristic of autistic children. Communication styles and preferences will vary based on the child and depending on the severity of ASD; the child may be nonverbal or verbal only with their loved ones. Communication styles can pose a challenge, especially when caring for nonverbal children as they may not be able to convey their emotions or needs. Parents are an

important source of information on the most appropriate communication and comprehension tactics for their child. It is imperative that nurses be aware of the communication style of preference for the child, and adjust their nursing care accordingly. Nelson and Amplo (2009) suggest that children on the autism spectrum may require alternative methods of communication, such as breaking the perioperative process into individual steps that are supplemented with simple visual aids such as a chart.

Gearner, Thompson and Tielsch-Goddard (2013) investigated the effect of implementing a visual chart to demonstrate the entire perioperative process to children with ASD. The chart included pictures of each step that the child would go through from the time they arrived at day surgery to the time they went back home. It was reported by both staff and parents, that visual charts served as an effective method of communication. Study results support utilizing visual aids to communicate with autistic children. However, parental feedback on the visual chart suggests that all of the steps should not be offered at once, as this can be overwhelming and cause distress. Rather, the perioperative steps should be presented one at a time with the identification of successful completion of each step prior to advancing through the next step in the perioperative process.

Perioperative Environment.

Effective communication and perceived satisfaction of the perioperative experience for autistic children and their families is also influenced by the perioperative environment. The day surgery environment is incredibly fast paced, busy, noisy, and can lead to a child feeling overwhelmed or experiencing stimulus overload. Nelson and Amplo (2009) and Short and Calder (2013), suggests that autistic children be separated from the chaos of the day surgery department, have limited auditory stimuli, and be slowly introduced to one piece of medical equipment at a time. While there has been no research evaluating or comparing the effectiveness of these suggested techniques, Drake et al. (2012) found that distraction items such as a toy, a large rubber ring to chew on or play with, a squidgy ball, and a light up spinning top all helped to distract the child during procedures. The development of a Coping Kit such as the one found in Appendix C, could take into consideration environmental, communication, and procedural modifications to optimize the perioperative experience for the child and their families. Encouraging parents to bring toys from home or create their own Coping Kit will also help create a positive environment.

Stakeholder Involvement

This Guideline was developed following consultations with key stakeholders including pediatric anesthesiologists and RNs with extensive experience in caring for autistic children undergoing day surgery. As well, an environmental scan of current nursing practice guidelines and in Canada was conducted which revealed a lack of current perioperative practice guidelines for RNs caring for autistic children undergoing day surgery.

Summary of Practice Recommendations

These practice recommendations are based on an integrative review of the literature and consultations with key stakeholders. If utilized appropriately, evidence supports that these practice recommendations could result in improved perioperative experiences for autistic children undergoing day surgery and and support evidenced based perioperative nursing practice with this population.

1.0 Continuity of Care

Recommendation 1.1 Confirm Diagnosis

At initial admission to the perioperative department, identify children with ASD by reviewing the medical records for confirmation of a diagnosis of Autism Spectrum Disorder.

Recommendation 1.2 Collaborate with Parents or Guardians

At the initial encounter, parents or guardians complete the “Perioperative Passport” to identify preferred communication techniques, sensory preferences, and other important information specific to the child.

Recommendation 1.3 Continuity of Nursing Staff

Perioperative dialogues between RN and families are established when a familiar face follows them throughout the perioperative process.

Discussion of the evidence. Perioperative RNs should utilize the information provided by the parents or guardians to modify their practice to meet the individual needs of autistic children and their families. Consulting the parents can identify preferred communication techniques, behavioural signs of distress, sensory preferences, and other important information specific to the child (Gearner Thompson & Tielsch-Goddard, 2013; Nelson & Amplo, 2009). Individualized plans of care can then stem from the information provided by the parents, and can aid in the delivery of effective nursing care and a positive perioperative experience for both the child and the parent. Perioperative dialogue between the RN, child and parents is established when a there is a consistent, familiar face following the child throughout the perioperative process. Having a perioperative RN who is familiar to both the child and parent, will ease anxiety and improve cooperation (Lindberg, von Post, & Eriksson, 2012). Creating a comforting perioperative environment for the child also stems from limiting the number of new healthcare personnel the child encounters during their visit (Benich et al., 2018).

2.0 Environmental Modifications

Recommendation 2.1 The Sensory Room

Autistic children and their families will wait in special sensory room, with limited auditory stimuli away from the noise and pace of the general waiting area.

Recommendation 2.2 Introduction of Medical Equipment

During each phase of the perioperative process, medical equipment will be slowly introduced one piece at a time to reduce the risk of hyper or hypo stimulation for the child.

Discussion of the evidence. The day surgery department is incredibly fast paced, busy, noisy, and can lead to a child feeling overwhelmed or experiencing stimulus overload. Nelson and Amplo (2009) and Short and Calder (2013) suggest that autistic children be separated from the chaos of the day surgery department to a room where they will be exposed to limited auditory stimuli and greater amounts of visual stimuli. Key stakeholders concurred that a designated room for ASD children is warranted to reduce the stress associates with the day surgery environment. As well, children with ASD should be slowly introduced to one piece of medical equipment at a time; approaching the child with several pieces of equipment that require excessive tactile stimulus can be very stressing to the child and cause them to feel overwhelmed. Research has shown introducing one piece of equipment at a time can reduce the stress experienced by autistic children undergoing day surgery.

3.0 Procedural Modifications

Recommendation 3.1 First on the List

Scheduling children with ASD to be first on the list can help to reduce wait times and subsequent fasting times. As a result, children experience less disruption in their normal routines which has been linked to more positive perioperative experiences.

Recommendation 3.2 Encourage Parental Presence

Encouraging parents or guardians to be present during the pre and post op period helps to alleviate the distress experienced by the patient.

Recommendation 3.3 Reduce Wait Times

Moving patients through the process as quickly and safely as possible reduces distress.

Recommendation 3.4 Visual Aids

Use the “Coping Kit” and “My Surgery Day” to manage the perioperative process.

Discussion of the evidence. Literature suggests, and key informants concur, that the rules and regulations surrounding the perioperative department be flexible enough to best meet the needs of autistic children. By introducing strategies to reduce wait times, and subsequent fasting times, children experience less disruption in their normal routines which have been linked to more positive perioperative experiences (Benich et al., 2018; Delaney et al., 2015). Gearner, Thompson and Tielsch- Goddard (2013) and Nelson and Amplo (2009) propose that effective perioperative planning involve organizing the day surgery list in such a way as to accommodate the needs of children with ASD, and this includes speeding them through the process as quickly and safely as possible. As well, allowing parental presence throughout each step of the perioperative process has been suggested by key stakeholders, as necessary to alleviate the distress experienced by the child. Environmental and procedural modifications can be simple, small steps but they can have a major impact on the perioperative experience.

Research suggests that visual aids are not only an efficient communication tool for autistic children, but are also a highly feasible and cost-effective method that could be utilized regularly by nurses in any day surgery department (Vaz, 2013). The “My Surgery Day” is a visual aid that can help the autistic child manage the perioperative process (Appendix C) and the “Coping Kit” includes visual aids that can be used as distractors for autistic children undergoing the perioperative processes leading up to their day surgery procedure (Appendix D). With the “My Surgery Day” visual aid, the child places a sticker in each box to visually represent the completion of that phase of the process including: the “check-in”; the assessment; putting on the arm band and pajamas; going into the OR; leaving the post-op recovery room, and going home. Asking the patient to paste or tape the stickers to the “My Surgery” sticker chart is a visual cue to the successful transition through the phases of the day surgery process. The Coping Kit is inclusive of several distractor items can help manage the process by keeping the child’s mind busy and diverting their focus away from the upcoming surgical procedures (Rudolph, 2016).

Conclusion

This Guideline provides RNs with evidence-based recommendations for the effective assessment and management of autistic children undergoing day surgery throughout each step of the perioperative process. These recommendations are supported by current evidence and while they are cost effective and feasible, they will require organization approval prior to implementation.

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Appendix A. My Perioperative Passport

This information will be used to support your child as they pass through the different phases of day surgery from admission to recovery.

My child communicates best through…

_____

_____

_____

My child responds best to...

_____

_____

_____

My child dislikes...

_____

_____

_____

Any other information that would be useful to help us care for your child during day surgery?

_____

_____

_____

Appendix B. My Surgery Day!

CHECK IN

Paste the sticker in the square after you have checked in.

CUT AND PASTE STICKER

ASSESSMENT

Paste the sticker in the square after your assessment.

CUT AND PASTE STICKER

BRACELET AND PAJAMAS

Paste the sticker in the square after you get the arm band and put on you Pajamas.

CUT AND PASTE STICKER

MY TURN!

Paste the happy face sticker in the square when it is your turn.

CUT AND PASTE STICKER

POST OP ROOM

Paste a sticker in the square after you wake up in the post op room.

CUT AND PASTE STICKER

GOING HOME!

Paste the home sticker in the square when you are ready to go home. This is the best step!

CUT AND PASTE STICKER

Appendix C. Perioperative Coping Kit

This perioperative Coping Kit includes items that can be used as distractors for autistic children undergoing the perioperative processes and leading up to their day surgery procedure. The items are placed in a clear bag, given to each child upon registration at the day surgery department, and returned to the front desk prior to discharge. All items in the bag are washable, and will be disinfected as per agency policy following each use. Another option for parents, would be for the RN to provide a list of possible items that they could bring from home to make up their child's own Coping Kit. An example of the contents of the coping kits include:

1) A stretchy resistant band
2) Plastic kaleidoscope
3) Rubik's Cube
4) Stress ball
5) Printable activity sheets
6) Washable markers and crayons

The items within the perioperative coping kit are intended to be used at the child's discretion as often or as little as they would like during their time at the perioperative department. The RN assigned to care for the child should encourage both the child and the family members to engage in the activities provided by the coping kit.

Appendix B. Literature Review

PRACTICE GUIDELINES FOR REGISTERED NURSES CARING FOR AUTISTIC CHILDREN DURING THE PERIOPERATIVE PERIOD

Integrative Literature Review

By
Samantha Glover
Student # 201136124

Faculty of Nursing
Memorial University of Newfoundland

Introduction

Registered Nurses caring for autistic children undergoing day surgery need structured, systematic, and standardized practice guidelines to help them address the unique needs of this patient population. No two children with autism are alike and therefore, no two plans of care should be alike (Koski, Gabriels, & Beresford, 2016). Autism spectrum disorder (ASD) refers to a group of conditions that affect intellectual development, social interaction and communication ability (Nelson & Amplo, 2009). Children who are diagnosed with ASD have more frequent encounters with the health care system than those children without ASD, including primary health care, specialty care, day surgery, and acute care (Cummings et al., 2016). Furthermore, autistic children are more likely to present with challenging behaviors during encounters with health care professionals based on their difficulty coping with change in their daily routine, communication challenges, and impaired social skills (Gearner-Thompson & Tielsch-Goddard, 2013).

The perioperative setting is particularly distressing for autistic children because the environment and staff are unfamiliar, day surgery interrupts their daily routines, and there is an abundance of external stimuli such as overhead speakers, medical equipment, and chattering from other patients (Nelson & Amplo, 2009). Caring for autistic children undergoing day surgery is a challenge and requires an innovative approach to nursing care (Bultas, 2012). The purpose of this integrative literature review is to critique current research on best practice guidelines for the care of autistic children undergoing day surgery, examine the gaps in the literature surrounding existing nursing practice guidelines for this population, and explore strategies to address the nursing care needs of this population. This literature review will be used to inform

the development of a structured, systematic, and standardized practice guideline for registered nurses caring for autistic children undergoing day surgery**.**

Information Sources

Various qualitative research articles and grey literature were compiled using several search engines including CINHAL, PubMed, Science Direct, and Google Scholar. Literature was not limited to publication year or country, given the limited amount of research conducted on this topic. Research was inclusive of children aged 0 to 16, and was not limited based on gender. Research studies that involved children with a developmental disability other than ASD, were also included. Literature was limited to the English language only and to health sciences disciples only given the purpose of the review. Search terms used included CINHAL headings "perioperative nursing" AND "autism spectrum disorder", "children" AND "autism spectrum disorder", "perioperative management" AND "autism spectrum disorder", and "nursing practice guidelines". PubMed MESH terms included "ASD", "pediatric perioperative nursing", "autism spectrum disorder", and "perioperative care". General searches were also completed using Google for identification of prevalence, incidence, and related grey literature surrounding autism in children in Canada.

This literature review was used to help develop the best practice guideline for RNs caring for children with ASD during the perioperative period, and understand how these practices impact on the child's reaction to care. This literature review is inclusive of both quantitative and qualitative research examining the opinions of health care professionals and parents on the effects of various strategies to meet the unique needs of children with ASD.

Research Questions

What is the current state of research on best practice guidelines for the care of autistic children during the perioperative period?

Is there a need for best practice guidelines for registered nurses caring for autistic children during the perioperative period?

What are the nursing care needs of autistic children during the perioperative period?

How are nursing practice guidelines designed, implemented and evaluated?

Working Definitions

Key terms used throughout this literature review include; Autism Spectrum Disorder (ASD), day surgery, perioperative nursing, and best practice guidelines. Definitions of these key terms will be described in the context in which these terms will be referred too within the literature review.

Autism Spectrum Disorder (ASD). A medical diagnosis given to children who exhibit deficits in communication, behaviour, and sensory processing (Gearner Thompson & Tielsch-Goddard, 2013). Children with ASD may appear nonverbal, have literal ways of thinking, and prefer visual instruction over verbal commands (Gearner Thompson & Tielsch-Goddard, 2013). ASD children experience sensory overload, hyper- or hypo-sensitivity to touch, poor attention spans, and feelings of anxiousness or easily overwhelmed (Gearner Thompson & Tielsch-Goddard, 2013). The behaviors of a child with ASD can range from repetition and fascination, to withdrawal and isolation (Short & Calder, 2013).

Perioperative Nursing A specialized area of nursing care which requires the Registered Nurse to have a high-quality knowledge base that supports positive patient outcomes before and after surgery. The nurse must assume the role of a clinician, educator, advocate, and researcher while keeping the best interest of the patient at the centre of the care that they provide (AORN, 2015). Perioperative nursing can occur on an inpatient surgical unit or in an ambulatory surgery center. According to the Association of Registered Nurses of Newfoundland and Labrador (2015), the goal of perioperative nursing practice is to provide holistic care and support to patients and their families, in an effort to assist them in achieving optimal wellness before and after their surgical procedure. Perioperative Registered Nurses engage in interdisciplinary collaboration and utilize all available resources in order to provide well rounded care to all patients during the perioperative period (AORN, 2015).

Day Surgery Refers to patients who come to hospital from home, have their surgical procedure completed, and then return home the same day following their recovery period. Surgical procedures performed on an outpatient basis are elective and of non-emergency importance. The pediatric patient will arrive to the day surgery unit having fasted for at least eight hours prior and be at their optimal health for their surgical procedure. They will be assessed by a perioperative nurse (i.e., vital signs, health assessment, and changing into hospital issued pyjamas), an anesthetist, and their designated surgeon. The day surgery process can involve several hours of waiting and consume much of the day for the patient and their families. The families of the pediatric patient remain with the patient throughout each phase of the day surgery process. Immediately following the recovery phase, a Registered Nurse will review

discharge and homecare instructions with the patient and a family member or guardian prior to sending them home.

Practice Guidelines are. used to assist Registered Nurses in providing consistent, safe and high-quality care that is evidenced-based (White & Spruce, 2015). Practice guidelines are not only rooted in current research and evidenced-based practice, but also follow the standards of practice set forth by nursing professional governing bodies (AORN, 2015; White & Spruce, 2015). Practice guidelines serve as a compass and source of reference for Registered Nurses to maneuver through their clinical practice safely, especially through complex patient situations (AORN, 2015).

Literature Review

This literature review is presented in three sections with the first addressing the research question of current evidence for best practices when caring for children with ASD during the perioperative period, the second section exploring the perioperative needs of this population and the last section examining the need for best practice guidelines. This literature review also includes quantitative and qualitative research examining the opinions of health care professionals and parents on the effects of various strategies to meet the unique needs of children with ASD undergoing day surgery. The review begins with a discussion of the guiding theoretical model for this practicum; the Iowa Model of Evidence-Based Practice to Improve Quality of Care.

The Iowa Model of Evidenced-Based Practice

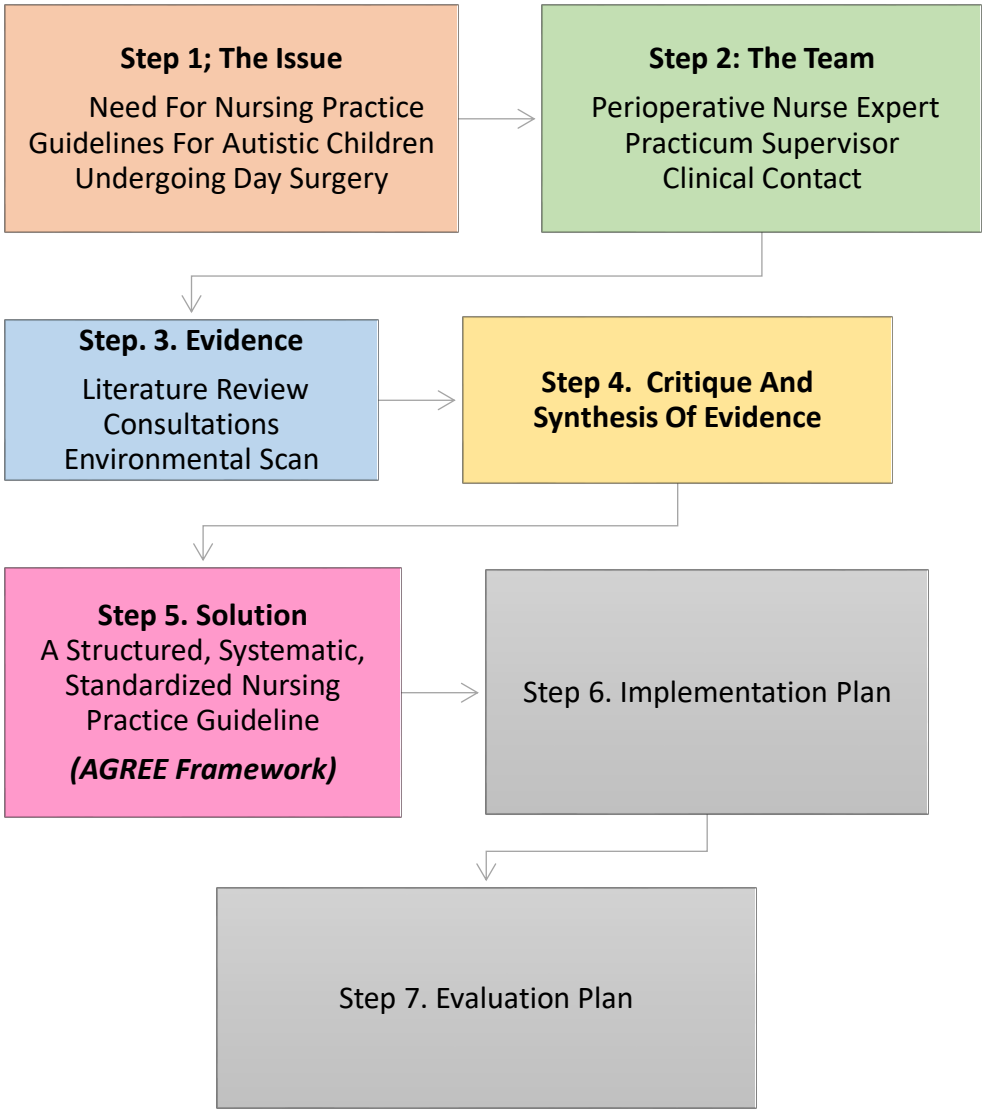
One theoretical model that can be used to guide the design, implementation and evaluation of an evidence-based best practice guideline for perioperative Registered Nurses is the Iowa

Model of Evidence-Based Practice to Improve Quality of Care (White & Spruce, 2015). The Iowa Model is one framework for clinical decision making that encourages critical thinking and collaboration before implementing current research findings in practice (White & Spruce, 2015). The goal of the Iowa Model is to ensure Registered Nurses base their practice on current evidence that support high quality and cost-effective nursing care (White & Spruce, 2015). By following this framework, the guidelines developed for this practicum project could bring awareness to the needs of autistic children undergoing day surgery, build on the current knowledge available on this issue and promote sustainable action.

The first step of the Iowa Model of Evidence-Based Practice involves identification and selection of a topic or issue. It is then determined if the issue stems from a problem-focused trigger such as evidence of a clinical problem, or from a knowledge-focused trigger such as new research findings. The issue identified for this practicum project is a knowledge-focused trigger and stems from current research on caring for autistic children undergoing day surgery. This issue is knowledge-focused given the absence of current standards and guidelines for nurses when caring for autistic children, yet new evidence to guide practice exists. At this step in the Iowa Model the topic is presented to the organization to determine if it is a priority and whether there is a willingness to support moving forward on the development of a solution to the proposed issue. In relation to this practicum, during this step the author consulted with key stakeholders and determined there was support for the development of guidelines and a willingness to move forward. Figure 1 depicts the Iowa Model applied to the need to develop best practice guidelines for RNs caring for autistic children.

Figure 1.

The Iowa Model Applied to Practice Guidelines



The next step of this model would be to include the identification and formation of a team inclusive of the key stakeholders involved with the issue that would be responsible for the collection of data, evaluation of research, development of solution, and implementation and

evaluation of the proposed solution. For purposes of this practicum project, the team consisted of the author, practicum supervisor, and clinical contact. The third step of the Iowa model involves the collection of relevant research and related literature, including consultations with stakeholders, and an environmental scan. The fourth step of this model requires a critique and synthesis of research findings and a decision if there is sufficient and reliable evidence to warrant the development of a pilot change in practice to address the issue. In Figure 1, the fifth step illustrates the project for this practicum, a structured, systematic, and standardized nursing practice guideline for RNs caring for autistic children undergoing day surgery.

A Framework for the Development of Best Practice Guidelines

The Appraisal Guidelines for Research and Evaluation for Health Systems (AGREE HS) is one framework that can be used to guide the development of the best practice guidelines for RNs caring for autistic children undergoing day surgery. The AGREE HS is designed to assist developers, policy makers, and key stakeholders in the development of quality health system guidelines (HSG) at a global, national, or provincial level (Brouwers, et al., 2019). A HSG contains evidence-informed recommendations for guidance and action to address justified health system challenges. The AGREE HS framework suggests that HSGs consist of five main components (i.e., topic, participants, methods, recommendations, and implement-ability). (AGREE-HS Research Team, 2018)

The topic refers to a detailed identification of the healthcare system challenge, arguments in support of its priority, and evidence that the guideline proposed is appropriate in addressing the challenge. Within this practicum, the topic is the development of best practice guidelines for perioperative Registered Nurses providing care to autistic children undergoing

day surgery. This topic poses a healthcare system challenge based on the defining characteristics of ASD, the associative comorbidities, the frequency of medical encounters with this population, and the current absence of specific standardized nursing practice guidelines. This topic is a high priority healthcare system challenge based on the increasing prevalence and incidence of ASD diagnosis amongst children in Canada and particularly NL.

The participants of the HSG development team to address the topic should include perioperative Registered Nurses, pediatric anesthesiologists, and nursing managers. The methods for the development of the HSG should be current, systematic, and transparent. The methods should include integrative literature reviews, a review of relevant grey literature, an environmental scan of current literature, and voluntary consultations with key stakeholders. Fortunately, the cost for the development of the proposed HSG for this project is minimal and only serves to benefit the population with no risk of causing harm. Finally, the recommendations from the proposed HSG will provide clear direction for perioperative Registered Nurses working in day surgery departments when providing care to autistic children.

Once the initial HSG has been developed and implemented, a plan will be put into place for updating the recommendations based on feedback from the organization.

The participants include the developers of the HSG, their professional backgrounds, and any influence of funding agencies. The methods refer to the utilization of both systematic and transparent methodology within the HSG, for example the use of an established framework such as the AGREE HS to guide the development of the practice guidelines. Recommendations of the HSG should be clear, comprehensive, address ethical considerations, and provide direction for practice. Implement-ability refers to the proposed strategies of dissemination,

acceptability, affordability, and flexibility offered within the HSG. When HSGs are developed in keeping with the AGREE HS framework they can be assumed to be of high quality and usability (AGREE-HS Research Team, 2018). The AGREE HS is therefore an appropriate framework to serve as a blueprint for the development of a high-quality best nursing practice guideline for perioperative Registered Nurses caring for autistic children undergoing day surgery.

Autism Spectrum Disorder

ASD is a lifelong developmental disability which varies in degree of severity of the common characteristics affecting communication patterns, behavior, social interaction, response to stimuli, and intellectual ability (Autism Society, 2019). The earlier the characteristics consistent with a diagnosis of ASD are identified in children, the earlier therapeutic management and treatment plans can be put into place. Thus, leading to improved quality of life for these children and their families (Autism Society, 2019). Children with ASD will often have frequent encounters with medical professionals given the comorbidities associated with the spectrum. Therefore, it is important for healthcare personnel to be familiar with how the variation in characteristics of ASD can present and how to care for children who are on all levels of the spectrum (Autism Society, 2019).

To date, there are no definitive diagnostic tests that exist to diagnose a child as having autism, rather, there are a list of observable characteristics outlined within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) suggestive of a diagnosis of ASD. The criteria for ASD includes:

> "*stereotyped or repetitive motor movements; inflexible adherence to routines; highly restricted, fixated interests that are abnormal in intensity or focus; and hyper- or hypo*

activity to sensory input or unusual interests in sensory aspects of the environment" (American Psychiatric Association, 2013, p. 50-51).

ASD is a lifelong condition affecting the functioning and processing mechanisms within the brain (Short & Calder, 2013). While there is no cure for ASD, there are alternative treatments and medications that can help manage the signs and symptoms of ASD (Nelson & Amplo, 2009). These treatments include changes in diet, addition of daily vitamins, or massage therapy (Nelson & Amplo, 2009). Given the diversity of a diagnosis of ASD it can be said that no two children with autism are alike and therefore, no two treatment plans should be alike (Koski, Gabriels, & Beresford, 2016). Children with a diagnosis of ASD are more likely to have frequent visits to the hospital given the comorbidities and complex medical management associated with their diagnosis (Benich et al., 2018). Therefore, it is critical that medical personnel have the proper awareness and knowledge of ASD in order to provide effective care for these children and their families.

Incidence and Prevalence of Autism

The incidence and prevalence of ASD is well monitored and documented by the National ASD-Advisory Committee (NASS) of the Public Health Agency of Canada (PHAC). NASS collects data from a variety of public sectors including health, education, and social services. A surveillance report on ASD released by PHAC in 2018 stated that in 2015, 1 in 66 children ages 5-17 in Canada were diagnosed with ASD. Comparably, in Newfoundland and Labrador (NL), 1 in 57 children ages 5-17 were diagnosed with ASD in that same year (PHAC, 2018). These statistics indicate a higher incidence of ASD amongst children in this province as compared to any other province in Canada.

When comparing the prevalence of ASD in Canada in 2015 to each province and territory, NL had the highest prevalence at 17.5 per 1,000 children as compared to the overall average of the country at 15.2 per 1,000 children (PHAC, 2018). Furthermore, NL consistently had the highest prevalence of ASD in children ages 5-17 since 2003 (PHAC, 2018). Overall, the prevalence of ASD amongst males is higher than that of females with the diagnosis being determined before 8 years of age (i.e., 72% of children in Canada received their diagnosis of ASD prior to their eight birthday) (PHAC, 2018). This is also true for the province of NL, where the prevalence of ASD in males was 28.8 per 1,000 (i.e., 2.9%) in 2015 as compared to the prevalence in females at 5.6 per 1,000 (i.e., 0.6%) in that same year (PHAC, 2018). With the high incidence and prevalence of ASD in NL, it is clear there is a need for best practice guidelines for RNs caring for autistic children undergoing day surgery.

Caring for Autistic Children Undergoing Day Surgery

Characteristics associated with a diagnosis of ASD can contribute to a child's maladaptive behaviors and negative responses to nursing care, especially during perioperative nursing care prior to day surgery (Gearner-Thompson & Tielsch-Goddard, 2013). Given the social, communication, sensory, and executive functioning difficulties experienced by autistic children, the unpredictable disruption in routine, overwhelming external stimuli, and unfamiliarity of staff of the day surgery unit can be distressing for children receiving perioperative nursing care. As a result, the practice guidelines for perioperative Registered Nurses should provide guidance in how to care for the complex and unique needs of children who fall anywhere on the autism spectrum.

A diagnosis of ASD affects how a child processes and responds within the perioperative setting. Since perioperative nurses often facilitate initial contact with children and their families coming for day surgery, it is important that they be knowledgeable about ASD and how to provide appropriate care to an autistic child. Most of the literature surrounding ASD in the perioperative setting is generalized to all healthcare professionals without specifically addressing the learning needs of the perioperative Registered Nurses (RNs), but it is also applicable to nursing.

The findings of the qualitative study by Benich et al. (2018) provide suggestions for perioperative caregivers to improve the care being given to autistic children and their families prior to day surgery including acknowledging the parents of the child as being the experts in their care, consulting with them to gather information about how best to interact with the child, and utilizing a standardized questionnaire to aid in the gathering of information for each individual child (Benich et al., 2018). Perioperative RNs are one of the most appropriate health care professionals to consult with parents, and families. If standardized questionnaires are used to gather information, Benich stresses that it is important to ensure that RNs are prepared to implement the questionnaire, interpret the responses and apply that information to their practice.

Comparably, a study by Gearner Thompson and Tielsch-Goddard (2013) found when perioperative nurses developed individualized plans of care based on such consultations with the child's parents, the perioperative experience for both autistic child and their families improved. Recommendations from this study suggest agree with Benich that perioperative RNs should be educated on how to develop individualized plans of care for autistic children and

their families prior to day surgery. This involves knowing how to conduct effective perioperative planning by maintaining a perioperative dialogue with the parents or caregivers of the autistic child throughout the perioperative period (Gearner Thompson & Tielsch-Goddard, 2013). Knowing how to care for autistic children includes collaborating with parents and families and developing individualized plans of care.

The Value of Parental Expertise

Parents or guardians often spend the greatest amount of time with their children, especially for children with developmental disabilities such as ASD. As a result, these parents or guardians serve as key informants, and are often the most reliable source of information for perioperative Registered Nurses prior to providing care to children with ASD (Koski, Gabriels, & Beresford, 2016). Consulting with the parents or guardians of these children can lead to identification of preferred communication techniques, behavioural signs of distress, sensory preferences, and other important information specific to the child (Gearner Thompson & Tielsch-Goddard, 2013; Nelson & Amplo, 2009). Individualized plans of care can then stem from the information provided by the parents, and can aid in the delivery of effective nursing care and a positive perioperative experience for both the child and the parent.

Benich et al. (2018) conducted a qualitative study to investigate the parental perceptions of their autistic child's perioperative experience. Results from this study emphasize the need for individualized patient centered care, and led to the development of a standardized parental questionnaire given prior to the child's perioperative journey. The completed questionnaires serve as a key communication tool to allow all members of the child's healthcare team to be aware of the individualized needs of the child, based on the parental

expertise. Gearner Thompson and Tielsch-Goddard (2013) also found such individualized treatment plans to be an effective method in providing specific perioperative nursing care to children with ASD when treatment plans included information provided by parents of the children. Maladaptive behaviours exhibited by the child were lessened, and consequently, the parental experience of the perioperative process improved based on parental involvement in the early stages. Ideally, the consultations with parents or guardians should occur prior to the child's initial perioperative encounter (Short & Calder, 2013).

The consultations and communication that occurs between parents and members of the healthcare team can be described as a perioperative dialogue (Short & Calder, 2013). The qualitative study results by Lindberg, von Post, and Eriksson (2012), reveal that parents felt their distress and their child's distress associated with the perioperative process was alleviated when they were included in the perioperative dialogue. Furthermore, when the needs of the child and the voice of the parents were well received and valued by members of the healthcare team, parental suffering was lessened and parents felt effective nursing care was being provided (Lindberg, von Post, & Eriksson, 2012).

While there has been minimal research investigating the nursing care needs of children with ASD undergoing day surgery, the research that has been conducted is suggestive of a need for an individualized plan of care that is formulated in collaboration with the parents or guardians and is developed prior to the commencement of the perioperative process (Benich et al., 2018; Gearner-Thompson & Tielsch-Goddard, 2013; Koski, Gabriels, & Beresford, 2016; Lindberg, von Post, & Eriksson, 2012).

Best Nursing Practices for Children with Autistic Spectrum Disorder

Collaborating with children, parents and families throughout the perioperative period is fundamental to best nursing practice. The information provided by the parents or guardians of the child, can lead to the development of an individualized plan of care which offers environmental, communication, and procedural modifications that will improve the perioperative experience for the child, their family, and the perioperative Registered Nurse. The unfamiliarity and unpredictability of the day surgery environment can be a trigger of stress and aggression for children with ASD, thus making the delivery of perioperative nursing care less than satisfactory for the children, their families, and the perioperative Registered Nurses (Nelson & Amplo, 2009). Therefore, it is important that Registered Nurses be cognizant of how the external stimuli and sensations are being interpreted by a child with ASD and take action to modify the environment to lessen the distress experienced by the child.

Benich et al. (2018) suggest children with autism be designated as the first patient of the day on the day surgery list in an effort to reduce wait times and fasting times for the child. Similarly, the study by Delaney et al. (2015) found an inverse relationship between parental satisfaction and length of pre-operative wait time. Gearner Thompson and Tielsch- Goddard (2013) and Nelson and Amplo (2009) propose that effective perioperative planning involve organizing the day surgery list in such a way to accommodate the needs of children with ASD.

Another evidence based best practice supported in the literature is the need for continuity and familiarity with an assigned perioperative nurse. In a study by Lindberg, von Post, and Eriksson (2012), parents report feeling helpless, hopeless, and suffering in silence when there wasn't a consistent health care personnel involved in the perioperative care of their

autistic child. The thought of encountering staff who lacked an understanding of the uniqueness of their child brought upon feelings of distress. Conversely, when perioperative dialogues were well established and one familiar face followed them throughout the perioperative process, parents felt their suffering was alleviated. Having a perioperative Registered Nurse whom both the child and parent recognized helped to ease anxiety and improve the cooperation and behaviors of the child during the perioperative process (Lindberg, von Post, & Eriksson, 2012). Overall, continuity and familiarity of perioperative nursing staff allowed for a more positive experience for both the child and the parents. Benich et al. (2018) also suggest that creating a comforting perioperative environment for the child stems from limiting the number of new healthcare personnel the child encounters during their visit.

Difficulties communicating and comprehending commands is a characteristic of children experiencing autism spectrum disorder. Communication styles and preferences will vary based on the child and depending on the severity of ASD; the child may be nonverbal or verbal to only their loved ones. The communication styles of these children can pose a challenge for perioperative Registered Nurses, especially when caring for nonverbal children as they cannot verbally convey their emotions or needs. Once again, the parents being the experts of their children would be an important source of information on the most appropriate communication and comprehension tactics for their child. It is imperative that perioperative Registered Nurses be aware of the communication style of preference for the child, and adjust their nursing care accordingly in order to provide optimal care to the child and their family. Nelson and Amplo (2009) suggest that children on the spectrum require alternative methods of communication,

such as breaking the perioperative process into individual steps that are supplemented with simple visual aids.

The study by Gearner, Thompson and Tielsch-Goddard (2013) investigates the effect of implementing a visual chart to demonstrate the entire perioperative process to children with ASD. The chart included pictures of each step that the child would go through from the time they arrived to the hospital to the time they went back home. It was reported by both staff and parents, that such visual charts served as an effective method of communication for children. Study results support perioperative Registered Nurses utilizing visual aids to communicate with autistic children. However, parental feedback of the perioperative chart suggests that the steps should not be offered to the child all at once, as this can be overwhelming for the child and cause distress. Rather, the perioperative steps should be presented one at a time with the identification of successful completion of each step prior to advancing through the next step in the perioperative process.

Similarly, a study by Chebuhar et al. (2013) found that perioperative picture schedules optimized the communication and perioperative dialogue between perioperative nursing staff, autistic children, and their parents. Parents reported such visual aids improved the behaviors of their child, their level of cooperation, and relieved the anxiety their children were experiencing due to the perioperative process. The development and implementation of a visualization tool is a rather simple solution to an otherwise distressing situation. Study findings by Vaz (2013) concur, that visual symbols are not only an efficient communication tool in the perioperative setting, but are also a highly feasible and cost-effective method that could be utilized regularly during the perioperative period.

Effective communication and perceived satisfaction of the perioperative experience for autistic children and their families is also influenced by the perioperative environment itself. The day surgery department is incredibly fast paced, busy, noisy, and can lead to a child feeling overwhelmed or experiencing stimulus overload. Nelson and Amplo (2009) and Short and Calder (2013), suggests that autistic children be separated from the chaos of the day surgery department, have limited auditory stimuli, and be slowly introduced to one piece of medical equipment at a time. While there has been no research evaluating or comparing the effectiveness of these suggested techniques, Drake et al. (2012) found that the use of a coping kit which involved similar tactics (i.e., introducing one piece of medical equipment at a time) reduced the stress of developmentally disabled children during their healthcare encounters. The development of a coping kit would take into consideration environmental, communication, and procedural modifications and could optimize the perioperative experience for the child and their families (Drake et al., 2012; Rudolph, 2016.

Research surrounding best practice guidelines for autistic children is primarily focused on the identification of the medical diagnosis, rather than the nursing care following the diagnosis. Research is further limited in identifying best practice or evidence-based practice guidelines for perioperative Registered Nurses caring for autistic children undergoing day surgery. While all AORN standards of perioperative nursing apply to caring for children with ASD, given the characteristics of a child with ASD and the consequent barriers to nursing care, there needs to be specific practice guidelines available to assist the Registered Nurse in providing quality care in the perioperative setting for this population.

While the study results by Benich et al. (2018) and Gearner Thompson and Tielsch-Goddard (2013) did not lead to the development of a specific best practice guideline for perioperative nurses, findings do suggest that future practice guidelines should involve perioperative nurses collaborating with parents of autistic children to develop an individualized plan of care to meet the unique needs of each child.

Standardized nursing practice guidelines are required for perioperative nurses caring for autistic children given the absence of current practice guidelines, the well documented barriers to nursing care, and the rising incidence and prevalence of ASD diagnosis. The development of a structured, standardized practice guideline would provide perioperative nurses with a source of direction when faced with the challenges of providing nursing care to an autistic child undergoing day surgery. Consistency in care has been well evidenced as optimizing the perioperative experience for the autistic child and their families (Benich et al., 2018; Lindberg, von Post, & Eriksson, 2012) therefore standardized practice guidelines would help to ensure consistency of nursing care for this population.

Standards of Practice for Perioperative Registered Nurses

The Association of Perioperative Registered Nurses (AORN) has established a set of standards to guide the practice of the perioperative Registered Nurse. The standards put forth by AORN suggest that perioperative nurses be committed to providing high quality, individualized, appropriate, and evidence-based care (AORN, 2015). Such standards are broad in scope and can be applied to all perioperative nursing practice. Perioperative RNs must adhere to the professional standards of the AORN when developing clinical practice guidelines to assist them through specific clinical situations; such as caring for an autistic child. Clinical

practice guidelines, or best practice guidelines, ensure that perioperative nurses provide safe, reliable, and cost-effective care to patients based on current evidence (White & Spruce, 2015). Given the rapid changing environment of today's world, it is crucial that perioperative Registered Nurses maintain current evidence-based practice guidelines in order to provide the highest quality of care. Given the uniqueness, vulnerability, and prevalence of the ASD patient population the development of best practice perioperative nursing guidelines to address the associated complex nursing concerns is undoubtedly warranted, but best practice standards for perioperative RNs should also adhere to the professional practice standards put forth by the AORN

Conclusion

Autism spectrum disorder (ASD) refers to a group of disorders that affect intellectual development, social interaction and communication ability (Nelson & Amplo, 2009). The characteristics and behaviors of a child with ASD can prove challenging for perioperative nurses when attempting to provide care to these patients in the day surgery department. In order to optimize the day surgery experience of the autistic child and their parents, the perioperative nurse must restructure their nursing practice and avail of the expert opinions of the parents to meet the unique needs of the child. Given the complexity and differences amongst children diagnosed with Autism Spectrum Disorder, there is a need for RNs to develop individualized plan of care, modify the perioperative environment and enhance visual communication methods for this population. The current research findings presented in this literature review suggests and supports the need for guidelines for perioperative Registered Nurses caring for autistic children undergoing day surgery.

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Appendix B-1
Research Literature Summary Table

Key Question: What strategies meet the unique needs of children with ASD undergoing day surgery?

Study/Design	Methods	Key Results	Comments/PHAC Rating
Benich et al., 2018 **Design:** Descriptive study **Aim:** To interview the parents of children with ASD for a description of their experience of the care their child received during the perioperative process, leading up to their child's otorhinolaryngology surgery.	**Country:** Australia **Sample:** 12 parents or guardians of children (0-18 years) with ASD who had undergone surgery in a tertiary medical centre in rural Australia within the last six months. **Data Collection:** Participants were recruited by a research assistant during their clinic visit, consent was obtained during a follow up phone conversation with the participant. The research assistant then conducted recorded telephone interviews using an interview guide that was developed in collaboration with the perioperative nursing team, surgical team, and the child-life program. The interviews were then transcribed by the research assistant. **Data Analysis:** The transcribed interview data was upload to the NVivo 11 starter software. Content analysis was completed to provide a descriptive overview and	**Node 1: Behavioral Triggers** 83% of participants said that loud noises triggered a behavioural outburst of their child. 67% of participants stated that their child had a preference for soft music 16% of participants said that sudden movements, change in daily routine, and long wait times were a trigger for a behavioural outburst, and introducing equipment slowly would be best. **Node 2: Objects Used for Comfort** 92% of participants discussed bringing toys from home as a comfort mechanism for their child. **Node 3: Communication Issues** 50% of participants described their child as non-verbal **Node 4: Important People** 100% of participants listed themselves as people who	**Strength of Design:** Strong since research findings were clearly related to research question **Quality:** Medium Small sample size Consistently uses one trained research assistant for data collection and analysis Transferability of results enhanced since parents of children with varying degrees of ASD were included Ethics approval and informed consent of all participants obtained

Study/Design	Methods	Key Results	Comments/PHAC Rating
	categorization of responses. Transcripts were then coded into "nodes" for taxonomic representation.	needed to be present to keep the child calm (i.e., before and after anesthetic). 33% of participants said that new faces were distressing for their child, therefore, consistency of staff personnel is important **<u>Node 5: Advice</u>** 50% of participants said shortening perioperative wait times would improve the experience for their child.	

Study/Design	Methods	Key Results	Comments/PHAC Rating
Chebuhar et al., 2013 **Design:** Descriptive **Aim:** To determine if parents felt that picture schedules for medical settings relieved the anxiety of children with ASD and determine if medical staff felt that implementing picture schedules in the clinical setting is feasible.	**Country:** Iowa, USA **Sample:** 17 participants including 6 nurses, 1 child-life specialist, one medical assistant, and 9 parents of children with ASD. **Data Collection:** Two surveys (one for parents and one for healthcare staff) used to evaluate the child's observed behaviors, distress level, and feasibility of using the picture schedule. Seven-point Likert scale was used for participants to rate their responses to the survey questions. **Data Analysis:** Descriptive frequencies	**1. Behavior Improvement** 87.5% of staff and 77.8% of parents felt picture schedules decreased anxious behaviors. One staff member felt picture schedule to be ineffective. 85.7% of staff and 88.9% of parents felt schedules decreased distress. 77.8% of parents felt picture schedules improved overall experience. **2. Parental Anxiety Alleviated** 77.8% of parents felt less distress in the presence of the picture schedule. 50% of parents expressed they felt less anxious about their child's return appointment. 3. **Feasibility of Implementing Picture Schedules** 75% of staff thought that using the schedules made it easier to complete the task. 100% of staff said they would be willing to use the schedule 100% of staff said that working with parents and receiving training on autism was helpful.	**Strength of Design:** Strong as the results directly related to the research questions. **Quality:** Medium Small sample size Surveys given immediately after exposure to the picture schedule Valid and reliable data collection instrument

Study/Design	Methods	Key Results	Comments/PHAC Rating
Delaney et al., 2015 **Design:** Prospective correlational descriptive **Aim:** To evaluate parental satisfaction with perioperative assessment, education, and the use of a computer instructional video.	**Country:** Illinois, USA **Sample:** 542 parents or legal guardians of children who had a perioperative appointment prior to a day surgery procedure between June 2011 and April 2012 **Data Collection:** The Preoperative Assessment and Education Questionnaire (PAEQ) which is a 23-item questionnaire was given to participants following their preoperative appointment. **Data Analysis:** Cronbach alpha = 0.96 Coefficients 0.85-0.99 Descriptive statistics (range, means, SD) Mann-Whitney U test used to determine differences in parental satisfaction for parents who watched the instructional video and those who did not. Spearman's Rho Correlation	Median scores for items on the questionnaire 1.0 (excellent) and 5.0 (very poor) **1. Parental Satisfaction** 76% of parents rated their experience as excellent **r= 0.751** ***p*<0.001** 20% of parents rated their experience as good Registered Nurse and Nurse Practitioner courtesy and respect mean= 1.20 and 1.23 Explanations about preop mean= 1.20 Answering questions mean = 1.26 **2. Parental Dissatisfaction** Length of wait time to be seen mean= 1.80 **r=0.433** ***p*<0.001** Receptionist explanation of pre-op appointment mean = 1.70 Promptness and efficiency of answers to phone calls mean= 1.58	**Strength of Design:** Strong as the results directly related to the research questions **Quality:** Medium Convenience sampling Appropriate statistical testing Reliable and valid statistical analysis

Study/Design	Methods	Key Results	Comments/PHAC Rating
Drake et al., 2012 **Design:** Post-test descriptive study **Aim:** To evaluate nurses' perceptions of the effectiveness of coping kit interventions in managing the challenging behaviours of children with developmental disabilities.	**Country:** USA **Sample:** 24 nurses over 3 pediatric in-patient units and Emergency department who have had experience in caring for children with developmental disability such as ASD, Down Syndrome, etc. **Data Collection:** Participants completed online surveys following the utilization of the coping kit during their shift. **Data Analysis:** Descriptive statistics (frequencies and ranges) and categorization of responses for identification of themes.	**1. Context of Use** Distraction during procedure (50%) Preparation for procedure (4.2%) Other uses (50%) **2. Child's Participation in Procedures** 12 nurses (50%) felt the kit increased the child's willingness to participate 19 nurses (79.2%) felt the kit resulted in positive coping and participation of the child during procedures **3. Behavioral Improvement** 19 nurses (79.2%) noticed a positive behavioral change in the child immediately following implementation of the kit 15 nurses (62.5%) stated that the child's stress was lessened in the presence of the kit 17 nurses (70.8%) stated they completed the tasks without behavioural outbursts following the implementation of the kit, however, only 4	**Strength of Design:** Strong as the results relate to the research questions **Quality:** Low Small sample Qualitative data collection and analysis was not used No validation or reliability of data collection methods mentioned

Study/Design	Methods	Key Results	Comments/PHAC Rating
		(16.7%) felt this was related solely to the kit.	
Gearner Thompson & Tielsch-Goddard, 2013 **Design:** Descriptive prospective study **Aim:** To collect information from families of children with ASD to develop an individualized plan of care and evaluate possible improvements to their surgical experience.	**Country:** USA **Sample:** 43 parents or guardians of children with a confirmed diagnosis of ASD who were undergoing a day surgery procedure. **Data Collection:** Two project investigators completed prospective chart reviews to identify patients with a diagnosis of ASD. Telephone interviews with parents were conducted pre and postoperatively. Information from the presurgical interview led to the development of patient specific handoff communication tools. Staff members of the surgical unit observed patient behaviors and recorded the occurrence and precipitating factors. **Data Analysis:** All data was analyzed by the two project investigators, categorized, and coded for themes.	**1. Patient Behavior Triggers:** 45% of adverse behavioral responses occurred when the child was having vitals taken 71% of adverse behavioral responses were precipitated by loud noises in the day surgery area. 2. **Parental Responses** Responses supported the importance of knowing details about the child's behavior and needs preoperatively in order to develop individualized plans of care. Visual charts to describe the preoperative to postoperative process is beneficial but only when steps are given one at a time instead of all at once.	**Strength of Design:** Strong **Quality:** Medium No mention of specific statistical testing Reliability and validity of instruments were not tested

Study/Design	Methods	Key Results	Comments/PHAC Rating
Lindberg, von Post, & Eriksson, 2012 **Design:** Descriptive hermeneutic approach **Aim:** To understand what parents of children with severe ASD experience in connection with their child's anaesthetics, in the presence and absence of perioperative dialogue.	**Country:** Sweden **Sample:** 12 parents or guardians of children (ages 5-16) who have a confirmed diagnosis of ASD and were scheduled for elective day surgeries **Data Collection:** Conversational interviews between researcher and participant. Interviews were audiotaped and notes were taken. **Data Analysis:** Gadamer's (16) hermeneutic text interpretation; transcribed verbatim, themes identified, and verified for accuracy by participants.	**1. Suffering in the absence of perioperative dialogues** A hopeless struggle Unspeakable suffering Disgraceful scenario **2. Alleviated suffering in the perioperative dialogue** Being received by warm hands Being received by a known face Subtle interplay between child and nurse	**Strength of Design:** Strong as the results directly relate to the research questions **Quality:** Medium Trustworthiness and credibility of responses was addressed Co-authors were also co-researchers strengthening the interpretation of data
Vaz (2013) **Design:** Descriptive **Aim:** To develop a variety of clinically appropriate symbols for use by parents and healthcare providers in various clinical settings and evaluate feasibility of these symbols in	**Country:** UK **Sample:** 50 healthcare professionals (physicians, nurses, dieticians, physiotherapists, occupational therapists, special needs teachers, and speech therapists) working with the pediatric population in hospital or in the community **Data Collection:** Informal surveys given to all participants to identify	**1. Event Timeline Symbols** All 50 staff members felt that the symbols representing the timeline of events to the child would be beneficial in explaining to the child the procedures being done. **2. Key Fob Symbols** 40 staff members felt the key fob symbols to be more	**Strength of Design:** Strong as results relate the research questions **Quality:** Low Small sample size Limited generalizability No quantitative statistical testing conducted No validity or reliability of survey was mentioned

Study/Design	Methods	Key Results	Comments/PHAC Rating
everyday use for pediatric patients with developmental disabilities	their opinions on the use of clinically appropriate symbols. **Data Analysis:** Transcribed verbatim and categorization for common themes.	practical given their portability and felt that teenagers would be more receptive to this format.	

Appendix C. Consultation Report

A STRUCTURED, SYSTEMATIC, AND STANDARDIZED PRACTICE GUIDELINE FOR REGISTERED NURSES CARING FOR AUTISTIC CHILDREN UNDERGOING DAY SURGERY

By
Samantha Glover
Student # 201136124

School of Nursing
Memorial University of Newfoundland

Purpose of Consultations

The development of a structured, systematic, and standardized practice guideline for perioperative Registered Nurses working with autistic children undergoing day surgery requires interdisciplinary and collegial collaboration. Consultations were conducted with colleagues (i.e., a pre admission clinic Registered Nurse and a Patient Care Facilitator) within the Janeway Children's Health perioperative department, pediatric anesthesiologists of the Janeway, and a Registered Nurse working in a pediatric perioperative department of IWK Health Centre. These consultations were intended to investigate the opinions of current nursing practice guidelines, and suggestions for future guideline development.

The "Appraisal of Guidelines for Research and Evaluation for Health Systems (AGREE HS)" (AGREE-HS Research Team, 2018, p.3) is a framework intended to assist in the development of health system guidelines, this framework was utilized in the development of a structured, systematic, and standardized practice guideline for perioperative Registered Nurses caring for autistic children undergoing day surgery. Following identification and justification of the topic, that is, the health system issue as a result of insufficient or non-existent nursing practice guidelines for this population, the second step of this framework involved identifying and describing key stakeholder involvement in the development of an appropriate health system guideline. The objectives of the consultations were as follows:

To identify the opinions of Registered Nurses on current practice guidelines when caring for autistic children while working in pre admission Clinics at the Janeway and at the previously identified pediatric hospitals of Canada

To identify the nursing practice guidelines when caring for autistic children that are being followed by Registered Nurses in pre admission clinics at pediatric hospitals across Canada, including IWK Health Centre.

To identify the opinions of the health care team on current practice guidelines when caring for autistic children while working in pre admission clinics at the Janeway and at IWK Health Centre.

Consultations were conducted via e-mail or face to face with key stakeholders and influencers to identify their opinions on the current practice guidelines for pediatric perioperative nurses, their evaluation of those guidelines in terms of applicability to the autistic population, and their recommendations for the development of appropriate nursing practice guidelines that will specifically address the needs of children on the autism spectrum. The data collected through these consultations will aid in the development of a structured, systematic, and standardized practice guideline for perioperative Registered Nurses that they can adapt when caring for autistic children, thus, improving the delivery and quality of care being provided.

Consultation Sample and Setting

Consultants were selected based on involvement and influence on the perioperative nursing care received by autistic children undergoing day surgery. Given that that purpose of the practicum is to develop a perioperative nursing practice guideline at the Janeway Children's Hospital, it was appropriate to consult Registered Nurses working within the day surgery department at the Janeway since they would be the individuals utilizing the newly developed guideline. Two Registered Nurses whom are currently working at the pre admission clinic at the

Janeway, which is a huge portion of the day surgery process, were consulted based on their direct involvement and experience of providing nursing care to autistic children preparing for day surgery. One of the two Registered Nurses, Patricia Brown, also serve as the Patient Care Facilitator for the pre admission clinic at this hospital. Patricia's responsibility is not only direct patient care, but also management and organization of care. Given her role within the perioperative department, it was important to consult Patricia on her opinions of current practice guidelines and suggestions for improvement. A Registered Nurse working within the pediatric pre-admission clinic at the IWK Health Centre was also consulted as a means of exploration and comparison of the nursing practice guidelines that are being employed at other hospitals of Canada.

Since the perioperative process involves multidisciplinary collaboration, it was appropriate to consult key stakeholders such as pediatric anesthesiologists. More specifically, an experienced pediatric anesthesiologist and the chief of pediatric anesthesiology at the Janeway Children's Hospital. Given their direct involvement and influence over the processes and procedures that take place within the perioperative department, it was necessary to explore their opinions on current nursing practice guidelines and suggestions for improvement.

Methodology

Data Collection

The consultations were conducted via e-mail, with the exception of the consultation with Patricia Brown, which was conducted in person at an office within the clinic. The e-mail addresses of consultants working at the Janeway Children's Hospital were retrieved from the Eastern Health employee directory. Consultants were asked the same series of open-ended

questions to examine their opinions on the learning needs of autistic children and perioperative Registered Nurses, current perioperative nursing practice guidelines, and suggestions for practice guideline improvement. See Appendix B for the questionnaire completed by each consultant. The Registered Nurse from IWK Health Centre was contacted initially via telephone from the departmental directory found on the IWK Health Centre website, followed by initiating contact through e-mail.

Ethical Considerations

An explanation of the proposed practicum was given to each consultant and voluntary consent was obtained. See Appendix A for the introductory e-mail explaining that purpose of the practicum and the need for consultation that was given to each consultant. The purpose of this practicum and consultation is quality and evaluation, and therefore, Research and Ethics Board approval was not necessary. All patient identifying information provided in the responses by consultants has been removed to maintain patient confidentiality.

Data Management and Analysis

Learning Needs of Autistic Children Undergoing Day Surgery

Consultants were asked what they felt the learning needs of autistic children undergoing day surgery were, and while responses varied, a common theme was extracted from the responses; every child is different. Autism spectrum disorder (ASD) includes a wide range of symptom and characteristic severity, therefore, it is inappropriate to generalize the learning needs of all autistic children. Rather, the learning needs of these children must be considered in light of their place on the spectrum, their age, and their developmental level.

Aside from the general consensus that the learning needs of these children are highly individualized, several consultants also reported that autistic children require familiarity of environment and procedure. Such responses provide further support on the opinion that this population has diverse learning needs that cannot be generalized. The recognition of a variation in learning needs will contribute to the development of a practice guideline that promotes and facilitates perioperative individualized plans of care for autistic children undergoing day surgery.

Learning Needs of Perioperative RNs Caring for Autistic Children

When consultants were asked to comment on their perceptions of the learning needs of perioperative Registered Nurses providing care for autistic children undergoing day surgery, there were a wide array of suggestions. The two anesthesiologists who were consulted both said Registered Nurses need to become more familiar with the features and characteristics of Autism Spectrum Disorder (ASD), once nurses understand what it means to have a diagnosis of ASD they can then tailor their practice to meet the unique needs of this population. The anesthesiologists both agreed there needs to be a standardized approach or algorithm to care of autistic children undergoing day surgery.

The pre-admission Registered Nurses who were consulted reported the learning needs were not necessarily what ASD is, but rather, knowing how ASD presents uniquely for each individual child. These consultants suggested the specific characteristics, needs, triggers, and communication style of each child as being the biggest learning need of perioperative Registered Nurses. According to consultants, guides to developing individualized nursing plans

of care for this population is lacking within the pre-admission clinic at the Janeway Children's Hospital.

Current Practice Guidelines for Perioperative RNs

Consultants were asked to comment on the current practice guidelines for perioperative Registered Nurses when caring for autistic children undergoing day surgery. The responses from consultants working at the Janeway Children's Hospital were consistent; there are no current practice guidelines to guide the practice of Registered Nurses caring for this population. Rather, consultants reported tailoring their personal nursing practice to meet the unique needs of this population. Consultants reported relying heavily upon parental expertise and the behavioural cues put forth by the child as the pre-admission process unfolds. Few consultants commented on the advantages of the development of nursing practice guidelines, and reported that such guidelines would assist in stream-lining autistic specific care. Conversely, such guidelines could cause nursing care to be strictly standardized rather than individualized, and therefore, fail to meet the unique needs of children with ASD.

The RN working at the pediatric pre-admission clinic at the IWK Health Centre, reported there are current practice guidelines in place to assist the Registered Nurses of the department in caring for autistic children undergoing day surgery. The program is called Balance, developed by a group of medical professionals with extensive training in dealing with children with a diagnosis of ASD. RNs working within the pre-admission clinic have detailed telephone interviews with parents prior to admission, where they will determine information specific to the child's needs and report this information to professionals at the Balance program. From this interview an individualized plan of care is developed for the autistic child and is carried out by

the perioperative team. The consultant felt that the advantage of this program is the individualized care that each child receives.

Recommendations for Guidelines

Consultants were asked to provide recommendations for future perioperative nursing practice guidelines that would optimize the care being provided to autistic children and their families undergoing day surgery. While there was no response from the consultant at the IWK Health Centre, the consultants working at the Janeway Children's Hospital had several recommendations that will be taken into consideration for the development of a nursing practice guideline for this population.

RNs working in the pre-admission clinic suggested future guidelines be versatile and accommodating to the individual needs of each autistic child. Consultants recommended that guidelines involve modifications to the perioperative process, such as; allowing the child to wear their own pyjamas rather than ones hospital issued, increasing parental involvement, booking the child first on the operating room list, and considering premedication administration. Anesthesiologists at the Janeway agree, perioperative Registered Nurses caring for this population require guidelines that are standardized, yet, flexible enough to allow for an individualized plan of care to be developed. The nursing guideline developed for this practicum should serve as a reference for a perioperative plan of care that asks parent's specific questions about their child and their needs in order to initiate a plan a care that will optimize the perioperative experience for the child and their family.

Conclusion

Conducting consultations with front line staff and those who are directly involved in the perioperative nursing process for children with ASD is necessary in order to develop a practice guideline that will be effective and accepted into practice. Based on the responses by each consultant, it is clear that there is a need for the development and implementation of a perioperative nursing practice guideline that RNs can utilize to provide optimal care to autistic children and their families. The consultations offered suggestions and opinions that will be considered during the development of a nursing practice guideline. There was a consensus amongst consultants, that nursing practice guidelines for this population ought to be standardized yet versatile enough to aid in the development of an individualized plan of care that is based on the unique needs of the child.

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AGREE-HS Research Team (2018). The appraisal of guidelines research & evaluation- health systems (AGREE-HS). Retrieved from: http://www.agreetrust.org.

BALANCE (2019). Retrieved from: http://www.balanceforautism.com

Appendix C-1: Consultation E-mail

Hello,

My name is Samantha Glover and I am a Registered Nurse completing my Master's Degree in Nursing at the Memorial University of Newfoundland. I am currently enrolled in the first of two practicum courses for this degree. For my practicum, I have decided to pursue the development of a structured, systematic, and standardized practice guideline for Registered Nurses caring for autistic children undergoing day surgery.

The rationale for this proposed project is there is an increasingly high prevalence of children diagnosed with Autism Spectrum Disorder (ASD) in Newfoundland and Labrador and their special needs can be a challenge for perioperative nurses. At present, there are no nursing practice guidelines that exist to assist the nursing staff of the perioperative department at the Janeway in providing care to autistic children undergoing day surgery.

I am requesting your cooperation in the completion of the attached questionnaire by the end of the day of October 21st. Your responses will be beneficial in the development of the practice guideline that will optimize the perioperative experience of the autistic child and their family. As well, the practice guideline will serve as a reference for perioperative Registered Nurses, to assist them in caring for the autistic child at the Janeway Children's Hospital.

Thank you for your time and input,

Samantha Glover

Appendix C-2: Questionnaire

What are the learning needs of autistic children undergoing day surgery?

What do you think Registered Nurses of the pre admission clinic need to know to provide care for these children?

Do you use any pre admission practice guidelines when caring for the autistic child undergoing day surgery?

If so, what are the advantages and/or disadvantages of these pre-admission practice guidelines?

What should be included in practice guidelines for Registered Nurses caring for autistic children undergoing day surgery?

Appendix D. Environmental Scan Report

A STRUCTURED, SYSTEMATIC, AND STANDARDIZED PRACTICE GUIDELINE FOR REGISTERED NURSES CARING FOR AUTISTIC CHILDREN UNDERGOING DAY SURGERY

By
Samantha Glover
Student # 201136124

School of Nursing
Memorial University of Newfoundland

Purpose of the Environmental Scan

The purpose of this environmental scan is to conduct a quality review and evaluation of existing guidelines and standards for perioperative Registered Nurses (RNs) when caring for autistic children and their families undergoing day surgery. The findings from the scan will be used to develop a structured, systematic, and standardized practice guideline for perioperative RNs working with autistic children undergoing day surgery at the Janeway Children's Hospital. A scan of current nursing practice guidelines and standards, both in Newfoundland and Labrador (NL) and Canada wide, will aid in the identification of any gaps in the current perioperative nursing practice guidelines when caring for this population and will inform the development of the content for the practice guideline being developed for this practicum project. The objectives for the environmental scan were as follows:

1. To review the CRNNL Standards of Practice for Registered Nurses and Nurse Practitioners (2019) in relation to caring for the autistic children undergoing day surgery.
2. To review and evaluate the perioperative nursing practice guidelines at the Janeway Children's Hospital surgical daycare specific to caring for autistic children.
3. To review and evaluate current, Canadian perioperative nursing practice guidelines and standards of practice in relation to caring for autistic children.
4. To review and examine one Canadian perioperative program developed for autistic children undergoing day surgery.

Methodology

Information Sources and Data Collection

This environmental scan utilized several sources of information to review and critique current nursing practice standards and guidelines for perioperative RN within Canada, more specifically, nurses working at the IWK Health Centre in Nova Scotia and the Janeway Children's Hospital in Newfoundland. RN working within Newfoundland and Labrador are guided by the College of RN of Newfoundland and Labrador (CRNNL) Standards of Practice for RN and Nurse Practitioners (2019). These are the standards of practice followed by all RNs in NL and therefore it is appropriate to review the standards for specificity and suitability for guiding the nursing care of autistic children undergoing day surgery.

Since this practicum involves developing guidelines for perioperative nursing practice within the day surgery department at the Janeway Children's Hospital, practice guidelines available on the day surgery unit and information within the RN orientation to the unit were reviewed. The guidelines and information were reviewed for their applicability to providing guidance for RNs when caring for an autistic child and their family undergoing day surgery.

Based on the consultation with a perioperative RN from the IWK Health Centre in Nova Scotia, it was deemed appropriate to review the College of RN and Licensed Practical Nurses of Nova Scotia's Collaborative Care Guidelines for Perioperative Nurses (2013). Those guidelines were available online and were reviewed and evaluated in relation to guiding perioperative RNs when caring for autistic children undergoing day surgery. As well, based on consultations with a perioperative RN, a program entitled BALANCE was identified that provides guidance to nurses

caring for autistic children in the department. An online module within this program, BALANCE: Surgery Edition, will be reviewed and discussed during this environmental scan report.

Perioperative RN practicing in Canada, are guided by individual provincial regulatory bodies and the National Association of PeriAnesthesia RN of Canada (NAPANc). The NAPANc offers clinical practice guidelines and standards that provide direction for perioperative RN working with all populations. The guidelines found on the NAPANc website were reviewed and evaluated in relation to caring for autistic children undergoing day surgery. The data collected through this environmental scan will be evaluated for appropriateness and adequacy to guide perioperative RNs caring for autistic children undergoing day surgery.

Ethical Considerations

The purpose of this environmental scan within this practicum project is to conduct a quality review and evaluation of existing guidelines and standards for perioperative RNs when caring for autistic children. Since the data collected is published on credible websites that are open to public viewing or published in an orientation package provided to new RNs of the Janeway Children's Hospital day surgery department, there will be no need for consent or permission of sharing data. As well, given the nature of the practicum, there will be no need to consult the Health Ethics Review Board as there are no foreseen threats to participants.

Data Analysis and Management

The College of Registered Nurses of Newfoundland and Labrador

The CRNNL, formally known as the Association of Registered Nurses of Newfoundland and Labrador (ARNNL), has put forth a set of standards that all Registered Nurses must uphold in order to maintain a practicing nursing license in the province of Newfoundland and Labrador.

The Standards of Practice for RN and Nurse Practitioners (2019), is a document inclusive of the most up to date nursing standards based on current evidence. While there is no specific reference to perioperative RN providing care for autistic children undergoing day surgery, there are components of these standards that will aid in optimizing the care provided to this population.

One of the identified practice standards that applies to caring for this population is that RNs must be responsible and accountable for their own nursing practice (CRNNL, 2019). This standard is particularly applicable for perioperative RNs at the Janeway Children's Hospital because according to orientation documents, RNs are expected to engage in learning and development opportunities to enhance and refine their knowledge of ASD, and how best to provide the necessary nursing care to this population. The second standard that directly applies is that the RN is expected to consistently using evidence-based knowledge in decision making and clinical practice (CRNNL, 2019). For perioperative RNs, this standard is suggestive of the development, communication, and implementation of an individualized plan of care for the patient using critical inquiry. More specifically for the population of autistic children undergoing day surgery, critical inquiry with the parents of the unique characteristics of the child will lead to the development of a perioperative individualized plan of care.

Similarly, the standard of client centered practice also suggests that perioperative RNs involve the parents of autistic children. Given the important role that a parent plays in a child's life, especially a child with ASD, consultation and collaboration with the parents is necessary in order to provide true holistic client centered nursing care. Lastly, the standard of maintaining professional relationships and leaderships can be utilized by perioperative RN to encourage

inter-professional collaboration. Autistic children with complex needs may benefit from a multidisciplinary health care team, perioperative RNs caring for these children should keep the lines of communication open amongst all team members for the benefit of the child.

Practicing RNs should utilize the standards outlined by CRNNL (2019) in collaboration with clinical guidelines based on their scope of practice as defined by CRNNL (ARNNL, 2006). The perioperative RN caring for children with a diagnosis of ASD must consider their scope of practice for decision making. According to CRNNL (ARNNL, 2006), RN are encouraged to consult their agency for specific policies and support regarding all clinical practice and decision making. For perioperative RNs at the Janeway Children's Hospital, there are no specific policies or standards of care surrounding perioperative nursing care for autistic children undergoing day surgery. In other words, there are no specific policies that exist to guide perioperative RN when planning and providing optimal nursing care to this population. There are no Janeway specific documents available at this department for RNs to refer to when providing care to children with a diagnosis of ASD to guide their practice.

IWK Registered Nurses

Unlike the general practice guidelines and standards proposed by CRNNL (2019), the College of RNs of Nova Scotia (CRNNS) and the College of Licensed Practical Nurses of Nova Scotia (CLPNNS) have developed collaborative nursing practice guidelines specifically for perioperative nurses (2013). This online document provides guidance to nurses at each phase of the perioperative experience, however, for the purposes of this practicum only the preoperative phase will be reviewed during the environmental scan.

The CRNNS and CLPNNS (2013) suggests that all perioperative nurses should work in collaboration with one another while keeping the client engaged in the plan of care and each step of the preoperative process. The guidelines by CRNNS propose that RNs work within their scope of practice, this includes; conducting comprehensive patient and family assessments, developing individual nursing care plans, and coordinating the agreed upon plan of care. CRNNS state that the plan of care be initiated and developed during the pre-admission clinic visit prior to the day of surgery. As well, RN should validate the plan of care with the patient and family. Both CRNNS and CLPNNS (2013) encourage perioperative nurses to make clients active participants in their care in an effort to improve health outcomes and patient satisfaction.

Although there is no specific language to differentiate caring for an ASD child versus a child without a diagnosis of ASD, the CRNNS / CLPNNS (2013) guidelines apply to. RNs caring for autistic children and their families undergoing day surgery. Evidence has shown that involving the child and their families in their plan of care has a positive impact on the nursing care the child receives. By following the general guidelines put forth by CRNNS, RNs will have a reference to optimizing the care they provide and the experience of the child and their families.

BALANCE program. The BALANCE program was developed and is implemented at the IWK Health Centre in response to the increasing number of autistic children visiting the hospital. BALANCE is an acronym for Building Alliances for Autism Needs in Clinical Encounters (BALANCE for Autism, 2019). This evidenced-based program consists of online learning modules and are intended and designed to enhance the knowledge of ASD and improve the comfort level of healthcare professionals caring for children on with ASD. The modules within the BALANCE program encourage healthcare providers to create an environment conducive of

"PACE- consistent care" (BALANCE for Autism, 2019). This style of care involves partnering with parents and families, assessing needs of each individual child, developing an individualized plan of care, coordinating care appropriately, and empathizing with families of patients during each interaction with the healthcare system. The program was tested by fifty-eight staff members at IWK for feasibility and acceptability, with 100% of members agreeing that they were not only satisfied with the program, but that BALANCE was also helpful, would be helpful for other staff, and contained valuable information.

There are several editions of this program available to healthcare professionals, there is a Surgery Edition containing seven online learning modules that are offered to staff who play a role in the preparation of an autistic child going for day surgery. This edition involves an introduction to the BALANCE program, strategies for providing autistic specific care, the premise of a PACE approach to care, and videos that are intended to be shared with the autistic child and their families during their pre-admission appointments prior to the date of their day surgery. Unfortunately, the BALANCE modules, including BALANCE: Surgery Edition, are unavailable to personnel working outside of the IWK Health Centre. The BALANCE website contains information surrounding the program, evidence for the program, and contact information for leaders of the program, however, there are no on line modules available for RNs outside of the organization.

National Association of PeriAnesthesia Nurses of Canada

The National Association of PeriAnesthesia Nurses of Canada (NAPANc) have established standards of practice for RN specializing in perioperative nursing care (NAPANc, 2017). These standards are intended to be used as a guiding reference for nurses working in perioperative

departments across Canada. While there are numerous standards set by NAPANc (2017) for perioperative RN, not one of the thirteen standards include language to assist a nurse caring for an autistic patient. However, several standards are applicable when providing nursing care to this population.

Perioperative RN should uphold a standard of integral and effective nursing assessment, process, planning, and implementation (NAPANc, 2017). The perioperative nursing care experienced by an autistic child and their family members weighs heavily upon the initial nursing contact, assessment, and plan of care development. The development of an appropriate individualized plan of care by the perioperative Registered Nurse for an autistic child undergoing day surgery will set the tone for the entire perioperative, intraoperative, and postoperative experience and subsequent healthcare experiences for the child and their family. Similarly, NAPANc (2017) propose that quality management, risk management, and quality improvements reside with the perioperative nurses' ability to identify potential issues and barriers to effective nursing care. Therefore, NAPANc (2017) suggest the standard be 1:1 nursing for any patient with complex needs. Caring for a child with autism requires consideration of the behavioral, sensory, communication, and intellectual involvement of their diagnosis. Therefore a 1:1 ratio should be implemented whenever providing nursing care to autistic children and their families undergoing day surgery.

Recommendations

Based on the findings from the environmental scan it is evident that there are insufficient standards and guidelines available for perioperative RN caring for autistic children undergoing day surgery, especially for RN working at the perioperative department of the

Janeway Children's Hospital. However, the IWK has developed an excellent web-based resource available for RNs that could provide expect guidance for the RNs at the Janeway. Although the standards and practice guidelines are incredibly vague and non-specific for the unique needs and requirements of providing care to autistic children some apply directly to the care of this population including; continuing competencies to further develop knowledge on ASD, conducting detailed nursing assessments of the patient through 1:1 nursing, collaborating with the patient and their parents to develop, and initiate a multidisciplinary holistic plan of care early on in the perioperative process. As a result of the findings of this environmental scan, there is an obvious need for the development of a structured, systematic and standardized practice guideline for RNs caring for autistic children undergoing day surgery at the Janeway.

Conclusion

This environmental scan reviewed and critiqued nursing standards and practice guidelines currently available to guide perioperative RNs in Canada, as well as in NL and Nova Scotia. Standards and practice guidelines were reviewed for their applicability and specificity to the pediatric autistic population. While there are practice standards by the CRNNL, CRNNS, CLPNNS, and NAPANc that are applicable and useful to guiding nursing care for this population undergoing day surgery, the language lacks specificity to a diagnosis of ASD. The standards proposed by these governing bodies are generalized to an entire population without any modification for the unique needs and requirements of an autistic child and their families during healthcare encounters. The IWK Health Centre does offer online training modules through their BALANCE program for healthcare staff wishing to expand their knowledge and

expertise in caring for the autistic population, however, this program is not mandatory and is not available to RNs outside of this hospital.

Based on the results of this environmental scan, it is evident that there is a need to develop nursing practice guidelines for RNs caring for an autistic child undergoing day surgery at the perioperative department of the Janeway. This environmental scan provides adequate justification for the need to develop a structured, systematic, and standardized nursing practice guideline for the RNs working in this department when caring for an autistic child undergoing day surgery

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A critical appraisal of: Practice Guidelines for the Care of Autistic Children Undergoing Day Surgery using the AGREE II Instrument

Created with the AGREE II Online Guideline Appraisal Tool.

No endorsement of the content of this document by the AGREE Research Trust should be implied.

Appraiser:

Date: 29 January 2020

Email: smacdon@mun.ca

URL of this appraisal: http://www.agreetrust.org/appraisal/71873

Guideline URL:

Overall Assessment

Title: Practice Guidelines for the Care of Autistic Children Undergoing Day Surgery

Overall quality of this guideline: 6/7

Guideline recommended for use? Yes with modifications.

Domain	Total
1. Scope and Purpose	15
2. Stakeholder Involvement	20
3. Rigour of Development	35
4. Clarity of Presentation	19
5. Applicability	15
6. Editorial Independence	8

Scope and Purpose

1. The overall objective(s) of the guideline is (are) specifically described.

Rating: 4

This Guideline can be used as a resource when planning individualized care to meet the unique needs of this population. RNs will benefit from reviewing the recommendations and the evidence in support of the recommendations. No mention of the child \"health benefits from the guideline should be specific to the clinical problem or health topic\"

2. The health question(s) covered by the guideline is (are) specificallydescribed.

Rating: 5

How does a perioperative RN meet the individualized needs of a child diagnosed with ASD undergoing day surgery?

3. The population (patients, public, etc.) to whom the guideline ismeant to apply is specifically described.

Rating: 6

Perioperative RNs

Stakeholder Involvement

4. The guideline development group includes individuals from allrelevant professional groups.

Rating: 7

two pediatric anesthesiologists, a nurse patient-care facilitator of a pediatric day surgery unit, a nurse patient-care facilitator of a pediatric pre-admission clinic, a RN with extensive experience caring for autistic children undergoing day surgery, and a senior RN working at a pediatric pre-admission clinic.

5. The views and preferences of the target population (patients, public,etc.) have been sought.

Rating: 6 integrative literature

review

6. The target users of the guideline are clearly defined.

Rating: 7

Rigour of Development

7. Systematic methods were used to search for evidence.

Rating: 4 no search strategy identified see user. manual

descriptions

8. The criteria for selecting the evidence are clearly described.

Rating: 4 add inclusion criteria for selected

literature

9. The strengths and limitations of the body of evidence are clearlydescribed.

Rating: 6

10. The methods for formulating the recommendations are clearlydescribed.

Rating: 6

11. The health benefits, side effects, and risks have been considered informulating the recommendations.

Rating: 6

12. There is an explicit link between the recommendations and thesupporting evidence.

Rating: 6

13. The guideline has been externally reviewed by experts prior to itspublication.

Rating: 2 will address this in the

implementation plan

14. A procedure for updating the guideline is provided.

Rating: 1 will be addressed in the

evaluation plan

Clarity of Presentation

15. The recommendations are specific and unambiguous.

Rating: 6

16. **The different options for management of the condition or healthissue are clearly presented.**

Rating: 6

17. **Key recommendations are easily identifiable.**

Rating: 7

Applicability

18. **The guideline describes facilitators and barriers to its application.**

Rating: 2 will be addressed in

implementation plan

19. **The guideline provides advice and/or tools on how therecommendations can be put into practice.**

Rating: 6

20. **The potential resource implications of applying therecommendations have been considered.**

Rating: 6

21. **The guideline presents monitoring and/or auditing criteria.**

Rating: 1 to be

addressed in plan

Editorial Independence

22. **The views of the funding body have not influenced the content ofthe guideline.**

Rating: 7 not

applicable

23. Competing interests of guideline development group membershave been recorded and addressed.

Rating: 1 not

applicable

Created online at www.agreetrust.org 29 January 2020