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EXPERIENCES OF ADULTS WITH AUTISM SPECTRUM DISORDER AND THE
EMERGENCY DEPARTMENT

BY

SABRINA BRODOFSKI

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Submitted by

Sabrina Brodofski

In partial fulfillment of the requirements for the degree of

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The thesis examination committee certifies that the thesis and the
oral examination is approved

Supervisors:
Dr. Gina Martin
Athabasca University

Dr. Georgia Dewart Athabasca
University

External Examiner:
Dr. Carly McMorris
University of Calgary

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Dedication

I dedicate this thesis to everyone who has a diagnosis of autism spectrum disorder, to the caregivers of individuals with autism spectrum disorder, and to the healthcare professionals who treat individuals with autism spectrum disorder. I hope this research creates conversations about this disorder and the need for continuing research, on the need for further training and education for all health care professionals, and that policy advisors develop better ways of making the emergency departments more sensory friendly and accessible to this population.

Acknowledgements

First, I would like to thank my children – if it was not for the both of you having autism, I would not have had the inspiration to pursue this topic of research. Thank you both for learning about autism with me, for showing me a completely different way of viewing every situation, and for teaching me that I need to be cognizant of the sensitivities and diverse needs of my patients. Thank you for teaching me how to be a better nurse.

To my husband, I want to thank you for your unwavering support in my pursuits of furthering my education and for having deep and meaningful conversations with me about what it is like to be diagnosed with autism at the age of 40. Your ability to articulate how the environment impacts your ability to think, feel and process information was invaluable. Your willingness to discuss difficult thoughts and feelings allowed me to understand the literature on a personalized level.

To my co-supervisors Dr. G. Dewart and Dr. G. Martin, I cannot thank you both enough for your knowledge, guidance, and patience. Your ability to reign in my lofty goals and aspirations and transform it into the following thesis was incredible. Your ability to help me pivot from interviews to blogs as a data source to continue my research is appreciated beyond words can describe. I do not believe this would have been possible without your kind, gentle communication and countless hours of reading and editing. Thank you, thank you, thank you!

Abstract

The purpose of this thesis was to understand the experiences of adults with autism spectrum disorder in the emergency department. A literature review was conducted that showed a dearth of information on this topic. I utilized qualitative descriptive (QD) methodology to gain knowledge from blogs to learn about the phenomenology of autistic adults – or their caregivers – when seeking medical attention in an emergency department. This research revealed three themes that created barriers to healthcare: a lack of knowledge from healthcare providers as it relates to autism, patient sensitivities, and communication difficulties.

Keywords: autism, autism spectrum disorder, emergency departments, healthcare, qualitative descriptive, blogs, ethical autism research

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List of Abbreviations

ASD: Autism Spectrum Disorder

CNO: College of Nurses of Ontario

ED: Emergency Department

HCP: Health Care Provider

OAP: Ontario Autism Program

QD: Qualitative Descriptive

RN: Registered Nurse

VCS: Visual Communication Systems

Preamble – thesis structure

This thesis examines the experiences of adults with autism spectrum disorder (ASD) in the emergency department. In chapter one, I will first introduce the context and rationale behind wanting to complete this research as well as introduce key terms and definitions. Chapter two outlines the steps taken to complete the literature review with the accompanying search results. A more focused review of the literature is important to fully understand the depth and breadth of the issues that ASD patients have when accessing the ED. The methodology section provides details of the study and is discussed in chapter four. The results from analyzing the blogs yielded three main themes – sensitivities, communication and knowledge which is presented in detail in chapter five.   Chapter six is the discussion where the results are compared with the literature with chapter seven concluding this thesis.

Chapter 1: Introduction

Context

The environment of an emergency department (ED) is fast-paced, and healthcare professionals (HCP) working in this area of care must assess and treat as many patients as possible, as quickly as possible. Additionally, police officers may bring in patients under arrest yelling and expressing their dislike for their current state while ambulances rush patients in on stretchers. The lights are always on, the cardiac and intravenous machines beeping and buzzing with alarms, call bells ringing, people are crying and screaming in pain, and there can be agitated individuals pacing in the waiting room with security on standby.

Working as a registered nurse in both urban and rural ED gave me the experience of assessing and treating multitudes of individuals spanning all socioeconomic classes, as well as

various cultures, religions, and ethnic backgrounds. As such, I was able to assess and treat both physical and mental health concerns of all ages and stages of life.

Many nurses working in an ED, myself included, thrive on the energy and pace of the department. However, it was not until I had two kids of my own, both diagnosed with autism spectrum disorder (ASD), that my view of the ED drastically changed. Seeing the ED environment – that I used to love – bring both of my children to anxiety-laden tantrums, meltdowns and at times rendering them completely non-verbal made me realize that the ED is not as inclusive as I once believed. Was it possible that some of my previous patients had ASD and their agitation and behaviors were due to them being overstimulated? This made me think, in what ways could EDs change to better support the needs of the patients with ASD? It is in the context of this question that I began my Masters research.

Background

Autism Spectrum Disorder (ASD)

ASD is not a new diagnosis; however, the name and definition have changed over time. In 1911, Eugen Bleuler, a German psychiatrist, first labeled a set of behaviors that were considered "severe cases of schizophrenia" (Evans, 2013, p.4) as Autism. More recently, ASD has been defined by the Centers for Disease Control and Prevention (CDC) as "a developmental disability … [where] people with ASD often have problems with social communication and interaction, and restricted or repetitive behaviors or interests" (CDC, 2022, paragraph 1). Additionally, a term commonly used in articles or discussions surrounding ASD is 'neurodiverse' which has been used to describe someone diagnosed with a cognitive disability such as Autistic Spectrum Disorder (Dalton, 2013); whereby the term neurotypical is used to describe someone who does not have an ASD diagnosis (Jordan & Caldwell-Harris, 2012).

Although the term neurodiverse is often associated with ASD, it can also be used as an umbrella label to describe individuals with other developmental disorders such as ADHD, dyslexia and dyspraxia (Wiginton, 2021).

Healthcare among Individuals with ASD

Individuals diagnosed with ASD have a higher use of healthcare services due to greater rates of poor health and co-morbidities than those who are neurotypical (Walsh et al, 2021). With the California government reporting an increase of diagnoses by a staggering 273% (Zylstra et al, 2014) and the Government of Canada (2018) reporting 1 in 66 children and youth being diagnosed; the healthcare system needs to prepare for the increased demands required to care for this community.

A previous systematic review was completed to determine what barriers ASD patients and their caregivers had to accessing healthcare and to create a tool addressing these barriers discovered through their research (Walsh et al., 2020). The results of this review not only outlined barriers pertaining to the symptomatology of ASD, but also the three levels of healthcare: - patient, HCP, and the healthcare system itself. Although this review raised awareness of the inability for autistic patients to easily access healthcare, it was not specific to a particular environment; the primary environment for the healthcare services was within doctors' offices. This environment entails planned medical appointments and medical procedures occur, which focuses on visits that the patient could potentially prepare for in advance. Given how overstimulating the ED environment can be and because when it is a true emergency, preparation isn't feasible, this is an important area of inquiry. Especially considering the increasing prevalence of ASD in society.

Adults with ASD and EDs

Children and youth living with ASD in Canada have access to various supports and services. For example, Five Counties Children's Center in Peterborough Ontario is a community support that children and youth have access to up until the age of 18; afterwards they are discharged from services (Five Counties, 2021). The Government of Ontario also created the Ontario Autism Program (OAP) whereby they provide a 'childhood budget' to eligible individuals living with ASD which is supposed to help offset the additional costs associated with ASD (Government of Ontario, 2022). However, once the individual turns 18, this funding stops. The Children's Hospital of Eastern Ontario (CHEO) (2021) has autism services for children, youth, and their caregivers with services ending once the individual turns 18. Although these supports and services are beneficial and impact the individual with ASD in a general sense, none of these supports or funding options assist the individual within the ED.

The diagnosis of ASD lasts a lifetime, yet there continues to be a lack of research completed for or with adults with ASD -pertaining to their experiences when accessing ED's. Moreover, some individuals with ASD are not diagnosed in early childhood and therefore likely have never had exposure or benefits of accessing the highly specialized supports and resources to learn about their diagnosis, coping strategies or therapeutic interventions that may be required to access the ED as an autistic adult.

Theoretical Framework - Critical Disability Theory

Philosopher Max Horkheimer developed a program regarding social change – which later became the critical theory (Berendzen, 2014). The underlying premise is that there is an alternate society that was created due to the political influence (Linklater, 2007). The goal of critical disability theory is to shed light on the concept of ableism – meaning the preconceived attitudes and beliefs that individuals who are 'normal' have priority and receives preference, and

those who are 'abnormal' are discriminated against and often excluded systematically (Stanford, 2019). As previously established, adults with ASD have numerous barriers and challenges that prevent them from receiving proper healthcare, causing a tiered population – those who are neurodiverse receiving inferior healthcare to those who are neurotypical. To fully understand the issues and concerns raised through this research, it will be framed and presented using critical social theory.

When a doctor or a nurse does not understand what ASD is or does not make concessions to the environment it can increase the fear and anxiety of the individual with ASD. This combination can cause some ASD patients to react negatively, exhibiting "behaviors of concern such as aggression, property destruction, disruptive and self-injurious behavior" (Calleja et al, 2019, p.1) and can be punished with restraints (Salvatore et al, 2021). This research will investigate the lived experiences of adults with ASD to see how ableism impacts them; but also, what can be done to ensure the emergency department is more supportive.

Statement of Problem

As previously discussed, there has been an increase in the number of individuals who are diagnosed with ASD in recent decades. This population tends to report poorer health on a range of outcomes and more healthcare utilization; yet there is a research and knowledge gap of the experiences of autism in the ED, particularly for adults. This research will attempt to uncover what the experiences are, if there are any common themes that arise during the analysis and any potential recommendations. This is important to help direct policy and procedural changes to ensure people with ASD are receiving effective and efficient patient care in the ED.

Purpose

The broad purpose of this research is to learn about the experiences that adults who have a diagnosis of ASD have had within the ED setting.

Research Question

1. What are the experiences of adults who have a diagnosis of ASD when utilizing the ED?

2. Were there any barriers or facilitators that arose when seeking emergency care?

3. What do patients or caregivers think could improve their experience of care in the ED?

Chapter 2: Literature Review

Having established the context and background of ASD and the emergency department in the previous chapter; this chapter details the steps that were taken to conduct a literature review. A literature search was completed to identify academic literature that addressed adult populations with ASD and their experiences accessing care in an ED environment.

Search Strategy

In consultation with a research librarian, as well as two thesis supervisors, a search strategy was developed and completed in January and February 2022. Search terms used were categorized into three subheadings – population, context, and sub-population with Medical Subject Headings (MeSH) used as applicable. Three academic databases (Medline, PsychInfo and CINAHL) were searched. Table 1 outlines the search words and terms used as well as the number of records retrieved after duplicates were removed. An update was completed November 1, 2023, by returning to the three previously searched academic databases (Medline, PsychInfo and CINAHL) with no further articles to be included. Reference checking was also utilized to exhaust all articles pertaining to this subject.

Table 1

Search Words and Terms used for all databases.

	Search	Query	Records Retrieved
Population	#1	[Adult or Adults] AND	11,078,098
Context	#2	[Emergency Department OR Emergency Room] AND	183,228
Sub-Population	#3	[Autism OR ASD OR Autism Spectrum Disorder OR Asperger's OR Asperger's Syndrome OR Autistic Disorder OR Aspergers]	179

Study Selection

Inclusion and exclusion criteria

Inclusion Criteria To be included in this literature review, the articles had to be peer -

reviewed and written in English. Further, the articles had to pertain to the ED with the focus

being patients with ASD or providers of care. The articles could discuss any form of barrier the

patient with ASD experiences, initiatives, programs, or policies that pertained to ASD and

receiving care within the ED, as well as educational programs – or knowledge deficits pertaining

to ASD within the ED. There was no date range or geographic limit implemented given the

relevance of both historical and present-day research.

Exclusion Criteria An article was excluded if it was not written in English, was a

literature review of previous studies, or if the full-text article was unavailable for review. The

articles were also rejected if they only discussed the diagnostic criteria, specific pharmacological

treatment options for specific aspects of the ASD condition itself or any healthcare setting other

than the ED (e.g., doctors' offices, clinics). Articles that pertained to the reasons for the

utilization of the healthcare system rather than the experience once at the ED were also excluded.

Screening Strategy

All articles were reviewed first by the title. If the title appeared to be relevant, then the

abstract was also reviewed. If the abstract showed promise for inclusion, the article in its

entirety was reviewed and it was then accepted or rejected for the literature review. This process

was completed in September 2022.

Synthesis

The data was synthesized using a narrative approach as it allows the information to be

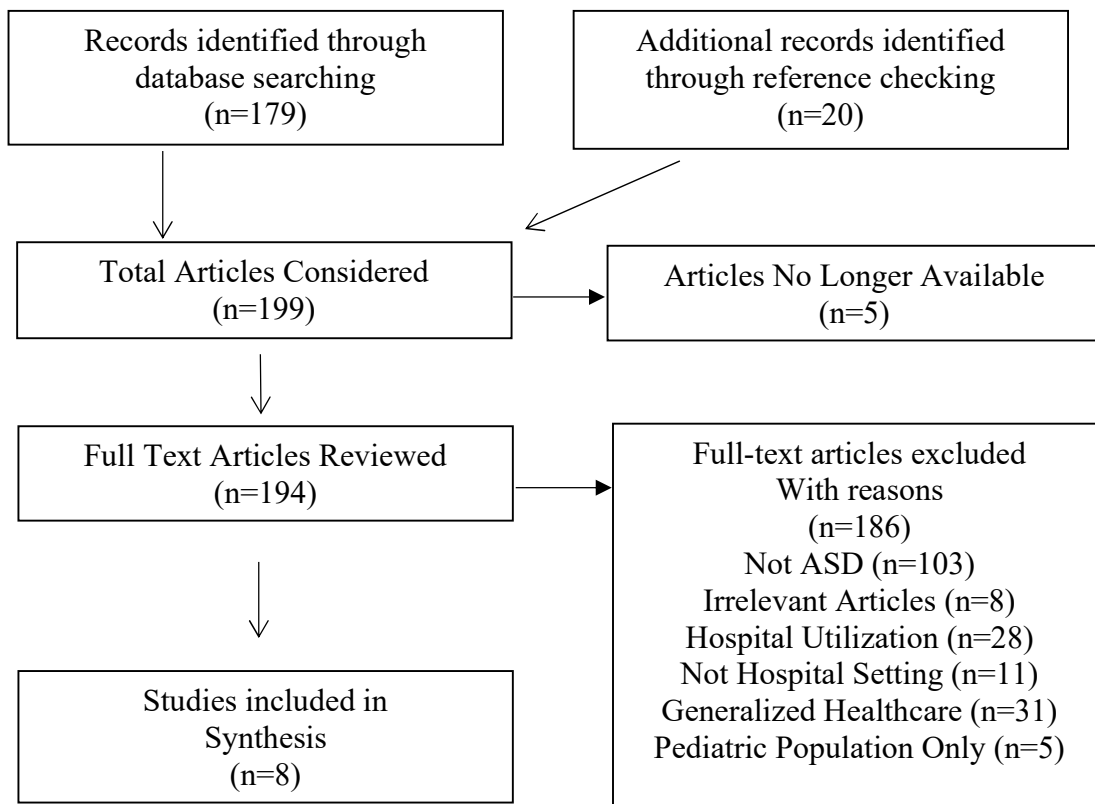compared both within the articles but with all articles within the literature review.

Search Results

The search yielded 179 results that were reviewed, with an additional 20 articles entered the review from reference checking. The systematic literature review screening results are reported using PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-analysis guidelines (University Libraries, 2021), see Figure 1.

Figure 1

PRISMA Flow Diagram

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┌─────────────────────────────┐      ┌─────────────────────────────┐
│  Records identified through │      │  Additional records         │
│  database searching         │      │  identified through         │
│  (n=179)                    │      │  reference checking         │
│                             │      │  (n=20)                     │
└─────────────────────────────┘      └─────────────────────────────┘
              │                                    │
              ▼                                    ▼
┌─────────────────────────────┐      ┌─────────────────────────────┐
│  Total Articles Considered  │ ───▶ │  Articles No Longer         │
│  (n=199)                    │      │  Available                  │
│                             │      │  (n=5)                      │
└─────────────────────────────┘      └─────────────────────────────┘
              │
              ▼
┌─────────────────────────────┐      ┌─────────────────────────────┐
│  Full Text Articles         │ ───▶ │  Full-text articles         │
│  Reviewed                   │      │  excluded                   │
│  (n=194)                    │      │  With reasons               │
└─────────────────────────────┘      │  (n=186)                    │
              │                       │  Not ASD (n=103)            │
              │                       │  Irrelevant Articles (n=8)  │
              ▼                       │  Hospital Utilization (n=28)│
┌─────────────────────────────┐      │  Not Hospital Setting (n=11)│
│  Studies included in        │      │  Generalized Healthcare     │
│  Synthesis                  │      │  (n=31)                     │
│  (n=8)                      │      │  Pediatric Population Only  │
│                             │      │  (n=5)                      │
└─────────────────────────────┘      └─────────────────────────────┘
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After the duplicates were removed, a total of 199 articles were considered at the title/abstract screening phase. After screening, eight (8) articles met all the inclusion criteria (Figure 1). Table 2 outlines the articles that were included in this review. Of the eight (8) articles, 50% (n=4) were completed in the United States, 25% (n=2) were from Canada and 25% (n=2) were from Australia. Half (n=4) of the articles involved healthcare professionals as their

population of focus and the remaining 50% (n=4) of the articles pertained to patients with ASD

and the ED.

Synthesis of the literature

Barriers

The most predominant thing this review found was that there are multiple barriers adults

with ASD experience when trying to access the ED. The top three barriers, or challenges,

expressed in these articles were (1) a lack of knowledge of health care professionals (87.5% of

studies or n=7), (2) the environment causing sensory issues (62.5% of studies or n=5) and (3)

communication issues between HCPs and adults with ASD (50% of studies or n=4) (Table 1).

These themes will be discussed separately with their own subheadings below. The studies

suggest that HCPs lack critical training and education to be able to alter the physical

environment of an ED or, to help prevent anxiety and aggressive behaviors stemming from

anxiety and sensory overload (Brasher et al, 2021; Salvatore et al, 2021; Mitchell et al, 2020).

They also found that no studies of adults specifically addressed the sensory issues the physical

environment causes, although it was identified as a key barrier (Nicholas et al, 2016; Salvatore et

al, 2021; Mitchell et al, 2020). Healthcare professionals also lack effective communication skills

to address and alter their interviewing strategies to meet the challenges the ASD community

experiences (Cashin et al, 2021).

Table 2

Summary of Included Articles

Author	Title	Country	Population	Setting	Information about the Study	Key Findings
Patients						
Brasher, S. et al, (2021)	Caring for Adults with Autism Spectrum Disorder in the Emergency Department: Lessons Learned from Pediatric Emergency Colleagues	United States	Parents, Adults	Emergency Department	Review of modifications made to the ED in a pediatric hospital that can be adapted to use in an ED that treats adults with ASD	-the authors suggest that a need for effective communication would translate from pediatric to adult patients -need to change environment to impact sensory perceptions -education for healthcare professionals -learn from pediatric community and apply it towards adult community
McGonigle, J. et al. (2014)	Development and evaluation of educational materials for pre-hospital and emergency department personnel on the care of patients	United States	Anyone who has ASD -Emergency Medical Services (Paramedics)	-Emergency Department	Describes the educational and training materials developed to be used when training ED staff	-education and training on the general topic of ASD – what is ASD, what the symptoms and characteristics of ASD are, discussions on the various challenges and potential solutions

	with autism spectrum disorder.					
Tint, A. et al (2019).	Emergency service experiences of adults with autism spectrum disorder without intellectual disability.	Canada	Adults (over the age of 17)	Emergency Departments	Qualitative study on the satisfaction with emergency services	-patients dissatisfied with care received within ED -more research pertaining to ED use and satisfaction within the ASD community required
Nicholas, D. et al. (2016)	Experiences of emergency department care from the perspective of families in which a child has autism spectrum disorder.	Canada	Children and youth (age 3-17 years of age) and parents (aged 31-51 years of age)	Emergency Department	Qualitative study using semi-structured interviews on the perspectives of ED care	-Barriers to care: ED process, ineffective communication, lack of education on ASD for healthcare providers, not utilizing parents as a resource, sensory issues of the ASD patient, lack of distractions from procedures, timeliness of assessment and treatment -recommendations: staff education, making care both child and family centered, advocacy for the ASD patient, ASD friendly team, modifications to wait times.

Healthcare Professionals						
Salvatore, G. et al. (2021)	Physician perspectives on severe behavior and restraint use in a hospital setting for patients with autism spectrum disorder.	United States	Physicians Medical Trainees	Hospitals	Qualitative research using focus groups and interviews on HCP	-Top five themes identified by the researchers: restraint use in emergency rooms as a way of coping with severe behavior caused by ASD -lack of knowledge re: restraint implementation -alternative methods to manage severe behaviors -limited experience treating patients with ASD -critical need for training
Giarelli, E. et al (2012).	Continuing Education for Nurses in the Clinical Management of Autism Spectrum Disorders: Results of a Pilot Evaluation	United States	Hospitals, tertiary care centers	Nurses	Evaluation project from a curriculum developed to teach nurses about ASD	-35% of participants were going to use their new knowledge to teach peers, 27% were going to apply it towards assisting ASD patients adjust in the hospital, 3% wanted to help draft policies, 5% was going to utilize their new

						knowledge when teaching new student nurses, 3% would refer those presenting with symptoms of ASD to be diagnosed, 8% wanted to work collaboratively with families to develop care plans and 19% had no comment.
Mitchell, M. et al, (2020)	Simulation-Based Education for Staff Managing Aggression and Externalizing Behaviours in Children with Autism Spectrum Disorder in the Hospital Setting: Pilot and Feasibility Study Protocol for a Cluster Randomized Controlled Trial	Australia	Hospitals	Nurses	Cluster randomized control trial to determine the effectiveness of simulation based education related to aggression and behaviours of ASD patients	-research design was completed, data collected, however, results not discussed in this article.
Cashin, A. et al. (2021)	A cross-practice context exploration of nursing	Australia	Hospitals	Nurses	Cross sectional descriptive study	-nurses who had experience working with ASD patients were

preparedness and comfort to care for people with intellectual disability and autism.	Various healthcare settings	significantly older than those who lack the experience, be employed in the private sector (opposed to the public sector) -education on ASD should be offered to increase confidence, knowledge -further research to assess the level of nurses working knowledge of ASD should be undertaken

Communication

Communication encompasses a variety of different skills that are impacted when you have ASD. Brasher et al. (2021) report that processing spoken words can take additional time, and often what is said is taken in its literal meaning. Nicholas et al (2016) found the literal translation and additional processing time often resulted in missed medical concerns and miscommunication. Bradshaw et al (2019) discussed in their study how ASD adults can often have difficulty finding the right vocabulary to fully relay their symptoms and their needs to the HCPs. This can mask health conditions that require emergency medical intervention (Brasher et al, 2016).   Bradshaw et al (2019) also reports that individuals with ASD can also use different language or gestures, and do not offer pertinent information about their symptomatology; rather they need to be asked pointed, direct, specific questions and at times during high stress situations, someone with ASD may have their ability to communicate altered and can become non-verbal.

The Emergency Department Environment- Sensory Issues

The ED can set off a chain reaction pertaining to an ASD patients' emotions and behavior. Nicholas et al (2016) found that among individuals with ASD this environment can cause anxiety due to being hyper-aroused. Brasher et al (2021) also found in their study that anxiety can then evolve into extreme behaviors because of over stimulation which directly and negatively impacts the HCPs ability to care for the ASD patient. The behaviors that Brasher et al (2021) discussed, Salvatore et al 2021 reports was managed using restrains: "applying restraint[s] is a common strategy for managing severe behavior despite associated increases in an individual's risk of depression, anxiety, and post-traumatic stress disorder following restraint implementation" (p.1).

Educating Health Care Professionals

Salvatore et al (2021) conducted focus groups and interviews with 25 medical trainees and early career physicians and found that overuse of restraints could be due to a lack of effective and efficient training. They reported that physicians expressed they had limited training and education on ASD and noted this is an area of improvement. These same physicians reported that it was through interacting with patients diagnosed with ASD, from completing reading on their own to increase their knowledge of the disorder, or through their mentors – that they learned about ASD. These physicians also noted they possessed a stigma towards ASD patients, making recommendations to reduce their stigma by providing training specific to ASD.

Physicians are not the only health care professionals requiring training and education pertaining to individuals with ASD. Brasher et al (2019) state nurses lack adequate training and education on ASD while in nursing school and again when transitioning to the workforce. This lack of knowledge can lead to negative or even traumatic experiences for ASD patients as crucial cues of escalating behaviors are often missed (Brasher et al, 2019). Mitchell et al (2020) discussed having simulated based training as a way of learning and coping with aggressive, escalated behaviors, although the results of this study were still outstanding.

Limitations of this Literature Review

For this review I completed the literature search, review, and synthesis. Although efforts to include all relevant articles were included, it is possible that some articles were missed, or that selection bias could be unconsciously present. Given the dearth of research focused on the needs of adults aged 18-64 with ASD, this review drew from some literature which considered a pediatric population as the recommendations for changes applied to the adult population, or due to the caregiver perspective. However, there may be unique needs of adults with ASD that are

not being considered, given the lack of research. Importantly, this signals a pressing need for research to inform the development of policies and best practice guidelines.

Recommendations for Future Research

To best serve the ASD community, research needs to be conducted on how adults with ASD can access EDs effectively and efficiently. This review sought to find evidence on experiences of adults with ASD accessing EDs to better understand more research is needed that examines the patients' perspectives and what patients would like to see happen to improve their ED experience. From the healthcare professional perspective, more research needs to focus on the specific knowledge deficits that are present as well as strategies and techniques on how to effectively interview and communicate with someone with ASD.

In sum, further research is needed to understand the patients' experience to inform and evaluate interventions that seek to improve this. Given the lack of research that addresses experiences of individuals seeking care at EDs, qualitative research may be an effective first step at developing a deeper understanding of the barriers and challenges adults with ASD face while accessing emergency care. Such research is foundational for developing systemic-level strategies to reduce these barriers. Further research also needs to be completed to understand the nurses' experiences when treating an adult with ASD. This will provide insight on any barriers or challenges nurses face from either an educational perspective, or from any policies or procedures that are in place that limit or restrict their ability to efficiently care for a patient with ASD.

Conclusion

The barriers and challenges of accessing healthcare for people with ASD among adult populations are not well understood with a dearth of research existing on the topic. Only eight

studies specific to adults with ASD and the ED were found, some of which are

commentary/opinion style. The lack of research highlights the need for a better understanding of

the experiences of adults with ASD and the ED. The proceeding chapters will outline my

research and results on this topic.

Chapter 3: Methodology

Preamble

This chapter will discuss the way in which the research was conducted. It discusses the rationale behind using qualitative descriptive (QD) as the chosen method as well as why blogs were chosen as a data source.

Introduction

This research utilizes a qualitative research approach. Broadly, qualitative research "is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem" (Isaacs, 2014, p.318). Qualitative research is non-numerical, meaning the data are in the form of the written word. It also considers how the values and beliefs of the researcher may influence the project. Given this, active reflection both before and during is required (Hignett & McDermott, 2013).

Although there are multiple different methods that could have been selected when completing qualitative research, I chose to use qualitative descriptive (QD). Qualitative descriptive (QD) research is a method used in completing qualitative studies when researchers want to know the "who, what, where and why" (Sullivan-Bolyai et al, 2005) of an experience. In the context of this research, it pertains to the experiences within the ED. QD can assist in illustrating challenges or barriers to evoke change and overall improve care (Sullivan-Bolyai et al, 2005) by collecting information directly from the source about their issues and concerns. This can be particularly useful in areas that involve the vulnerable population, as they can be under-researched and often not properly understood (Sullivan-Bolyai et al, 2005).

There are a few characteristics or features of QD methods that are appropriate for this study. It can be altered as the research is occurring, or even after the data has been collected and

themes are starting to emerge (Colorafi & Evans, 2016). This flexibility allows the researcher to

present the data based on a conceptual framework that is true to the data; opposed to trying to

have the data fit into a specific theory or framework. While I had a firm understanding of what a

diagnosis of ASD entailed, the trajectory of the results of the research was vastly unknown. The

ability to determine a conceptual framework after the research was completed allows the words,

thoughts, expressions to be heard without alteration to fit into a predetermined theory. This is

especially pertinent if the data collected presents unexpected findings that are pertinent to the

research question. Although semi-structured interviews are often used in QD (Neergaard et al.,

2009), I utilized blogs as a data source which allowed for a deeper understanding of the

participants' thoughts, feelings, and experiences. The blog authors were able to write about their

experiences in an environment that was comfortable for them, to share whatever information

they chose and to express themselves in a way where they could be their authentic selves. QD

allowed me to discover the various areas of the emergency department that may require change

to ensure adults with ASD can access healthcare with fewer barriers. This was accomplished by

allowing the impact from the descriptors used to explain and express experiences to flow through

the project by leaving the raw data unedited. Although it is acknowledged that a critique of this

type of methodology is that it is as "journalistic" (Chafe, 2017), given its focus on the

experiences of autistic adults and/or their caregivers within the ED, presenting the data and

findings in this fashion will ultimately allow for better communication of the experience of being

a person with ASD in the ED.

Research Design

Blogs as a data source

This research will utilize blogs as a data source for this study. A blog can be likened to a diary; where the author can record private, emotionally sensitive information, however instead of it being written in a book that is tucked away in a bedroom, it is shared on the internet for anyone to read (Hookway, 2008). Most blogs are descriptive in nature, some provide a commentary on a topic or can be used to share recent events (Hingle et al, 2013). After the blog post, there is a section where the reader can post comments about what they have read, their reactions to it – both positive or negative – and often conversations and dialogue can occur. Due to the way in which blogs are created, written, and expressed; it aligns with qualitative methodology. Blogs are especially pertinent to QD as the post is being written using the blog author's words to convey their emotions, thoughts and experiences and are written in a naturalistic environment.

Due to an increase in online postings, social media platforms – including blog forums - are not only being used to recruit participants for studies but are now an accepted source of data for research (Wilson et al, 2015). Olive et al (2015) used blogs to supplement their field notes when they conducted research on women and surfing. The rationale behind this was to ensure the researchers remained 'connected' with the greater surfing community, but also to collect more data. One benefit to utilizing blogs in research is the option to gain an understanding into the experiences of difficult to reach communities. For this study specifically, I was unsuccessful at obtaining participants for structured interviews due to factors such as timing, social anxiety, and a lack of follow through. By utilizing blogs, the blog author has already commented on their experiences and published it in a readily available forum. This allowed me to learn from individuals with ASD about their experiences within the ED – something I otherwise would not have been able to accomplish. While measures can be taken to protect the blog author's identity, ultimately the decision to post online for others to read.

Data Collection

To be considered for this research study, the blogs had to have been written by someone who self-identifies as having ASD between the ages of 18-64 or be a direct caregiver of an individual with ASD (based on caregiver description). Blog authors could be of any gender, race, ethnicity, culture, education level, and can reside anywhere in the world, however, the blog needs to be written in English and accessible to the public. To be excluded from the study, the blog author would need to fall outside of the age parameters, not written by an individual who identifies as having ASD or their direct caregiver, written in a language other than English, or was private/required a membership to view.

Ethical Considerations

Prior to the commencement of this research study, an application to Athabasca University's Research Ethics Board was obtained - see Appendix A for the ethics approval letter. Noted ethical concerns of the use of blogs in research are (1) the use of private versus public blogs and (2) the anonymity of a blog author versus treatment of the blogger as an author (Hookway, 2008). To address both issues, the researcher has opted to only use public blogs, meaning anyone can access them from completing a google search and no membership or 'friend' request is required. Another is the ability to remain anonymous; to state things they may not have felt comfortable speaking – which would then provide richer data (Hingle et al, 2013). Conversely, there are concerns about privacy, consent and if the material that is written is factual or fiction (Hingle et al, 2013). Additionally, as such, themes are presented in aggregate form without utilizing direct quotes from any of the blogs – which could be identifiable. All personal identifying information (such as names, screen names, town, or city of residence) are not

reported, which will ensure that any information utilized in this study will not be traced back to the original blog author.

Blog Search Strategy

Blogs were collected through the top three search engines (Forsey, 2023): Google, Bing, and Yahoo!. The search words used in all three search engines were "blog and autism and emergency". The first 25 search results – including sponsored responses – were reviewed for appropriateness. If the website or blog pertained to children only, general information on ASD or listed suggestions and recommendations to prepare for medical appointments by organizations, they were excluded. Duplicate blog sites were also removed. A total of five different websites that contained blogs were selected for further consideration – Autism B.C., 'The Autism Blog', NCSA (National Counsel on Severe Autism), The Arc and 'The Art of Autism'. Each of these five websites were searched using the words "hospital" and again with "emergency". A total of seven blogs met the inclusion criteria for this study.

Data Analysis

After collecting the blogs, I imported them into the software NVivo. Then I began to code the blogs. Coding is when the researcher reviews the data, extracts the salient points, and can organize it in a way that allows continuing analysis to occur (Formin, & Damschroder, 2008). In keeping with the QD methodology, I began reading the blogs and then started to compare the seven blogs together. If there were any words, descriptors, similarities, or blatant reiteration of items that stood out, they were coded. For example: I noticed that words such as 'light', 'sound', and 'education' were discussed in multiple blogs. This step occurred multiple times to allow the voices of each of the blog authors to speak; maintain their exact words, thoughts and ideas portrayed by the blog authors in their original form. After I was satisfied, I

began to group 'like' codes together. Words and discussions pertaining to 'light', 'sound', 'touch', and 'pain' were grouped together under the heading of 'sensitivity'. Any coding that could potentially be tied into communication – good or bad experiences, suggestions for improvement, from both the patient/caregiver and HCP perspectives were grouped together. Similarly, knowledge was the third theme that presented itself and any coding that pertained to education, training, knowledge, suggestions, or areas to improve knowledge were grouped together. As already eluded, the three main themes that were consistently reported pertained to communication, sensitivities, and knowledge. My rationale for performing the coding in this fashion was to allow for themes to naturally present themselves without any influence or assumptions made by the author. Initial and subsequent coding was reviewed by the authors' supervisors to ensure consistency and accuracy. To code in this manner followed the QD characteristics. I was able to maintain the words, thoughts and ideas portrayed by the blog author in its original form.

Expectations

Due to my experiences within the ED, as well as being a parent to two ASD children, I expected that there would be barriers involving various sensitivities. I also expected that the knowledge of the HCP may be called into question, however, I was not expecting communication to be a main theme that emerged during my study. To ensure the blog authors' experiences and perceptions were the focus and to allow for their experiences to be central to the findings, I actively participated in reflexivity during the entire process. I wrote in a private journal my own thoughts and feelings, ensured that what was being captured was not my own ideas and ensured the data was being described and presented in a way that kept their words –

unaltered. There was also communication with my thesis supervisors to ensure I was not

relaying any biases or assumptions into this study.

Chapter 4: Results

Introduction

This chapter presents the results of the analysis of the contents of the blogs as it pertains

to the three previously outlined research questions:

1. What are the experiences of diagnosed autistic adults in the emergency department?

2. Were there any barriers or facilitators that arose when seeking emergency care?

3. What do patients think could improve the experiences of care in the ED?

A discussion regarding the results is detailed further in the next chapter. To facilitate ease of

understanding, blog authors who have a diagnosis of ASD will be referred to as an individual

with ASD, or an autistic person/individual rather than blog author. For those writing from a

caregiver standpoint, they will be referred to as a caregiver – with the understanding the

individual they support is autistic.

Sample Description

There were only six blogs that met the inclusion criteria (as previously outlined in

Chapter 3) for this research study, with the demographical information of each author presented

in Table 3. Information pertaining to age, gender and country of origin was not openly discussed

or consistently reported. The age of the blog author or autistic individual was ascertained by

viewing their picture (if available), looking at their personal information regarding employment

or education level, or if it was stated in the blog itself that the individual with ASD was an adult

– despite not disclosing the exact age. Additionally, one individual with ASD described two

different experiences within the ED and wrote two blogs – one written in 2021 and the other in

2022. Of note, one individual with ASD had a doctoral level education and another was a

college graduate working as a journalist. The importance of illustrating the identified education

level is to highlight that the blogs were not chosen based on education or socioeconomic class –

rather the blogs were chosen as they described their experiences within the ED.

Table 3

Demographic information of blog authors

Year blog was written	Country of Origin	Gender	Age	Patient or Caretaker	Education
2021	Unknown	Undisclosed	Unknown	Patient	Doctorate
2022	Unknown	Undisclosed	Unknown	Patient	Doctorate
2020	Unknown	Undisclosed	Unknown	Collaboration of stories from caregivers	Unknown
2020	United States	Female	>45	Patient	College
2023	Canada	Non-binary	Unknown	Patient	Unknown
2019	United States	Undisclosed	Unknown	Caregiver	Unknown

One blog that described the experiences of supported ASD individuals was from multiple

caregivers – each describing their interpretation of events as it relates to their supported

individual.

The proceeding subheadings are used for ease of readability. 'The Blogs – in depth'

discusses greater details of each of the six blogs that were used in the study. Each of the three

themes – sensitivities, communication and knowledge are discussed separately and further

divided into the barriers and associated recommendations to solve the barriers as presented by the blog authors. The heading of 'facilitators' describes an item/action/procedure/skill used to potentially lead to a more positive experience within the ED.

The Blogs – in depth

Across the blogs, the reason for seeking emergency care varied as widely as the individual seeking it – from neurological issues to chest pain; allergic reactions to requiring emergency surgery. The following provides context as to the reason for seeking care and the care that was received while in the ED as outlined in the blogs from the autistic adults or their caregivers. One caregiver described multiple situations that required the autistic individual they supported to seek emergency care. In this account, the caregiver outlined three separate ED visits relating to a dislocation (of an unknown location) and accompanying minor fracture with the first experience, cellulitis with the second, and seizures for the third visit. Two of the three experiences resulted in the patient being physically restrained by multiple healthcare staff to try and perform diagnostic imaging or to provide treatment. However, the third time was when the patient had a seizure and was discharged home with instructions to follow up with an outpatient neurologist instead of providing an intravenous (IV), administering a sedative and conducting an EEG to try and assess the cause immediately after the seizure.

One autistic individual did not state the reason for their ED visit; however, described their experiences transitioning from a verbal communicator to becoming non-verbal, often because of overstimulation or experiencing social exhaustion. Another autistic individual describes an experience where their allergies had already required two separate ED visits within the past month where an ambulance was summoned to transport them to the hospital. After arriving at the hospital via ambulance, the blog author was told to go back outside and wait; and

was ultimately provided an injection of an antihistamine with the hospital arranging transportation for the blog author to return home. This individual required prescription-based allergy medication that they had run out of, and the hospital refused to prescribe more. The next visit they were sedated against their will and then experienced an allergic reaction to the sedative. No further information was provided about that visit.

One autistic individual sought assistance due to stabbing chest pain that radiated to the upper back with a secondary symptom of vomiting blood. This person has a medical background and understands they required medical attention. After preliminary tests returned normal results, the doctor diagnosed them with bulimia and medicated for nausea and pain; while the nurses determined the individual was suffering from anxiety and started to talk about her in the hallway, in front of other patients. After being discharged home, this individual decided to go to a different hospital who listened to the symptoms presented and a referral to a specialist was initiated. Interestingly, this individual attributed their poor experience partially to their gender – being female. They mentioned a study (no formal reference provided) that stated that women with ASD, compared with males with ASD are at a higher risk of poor health outcomes and stated its due to doctors being quick to "dismiss" a woman over a man. While this can be considered a barrier to accessing care, this was the only blog to bring this forward. Additional research would need to be conducted on whether gender impacts healthcare for ASD individuals more broadly.

One caregiver outlined a particularly concerning experience when an individual with autism entered the ED with stomach pains and was then discharged home from hospital. The next day, the patient returned to the hospital with a ruptured appendix. The doctor did not understand the patient's perception of pain and the surgery was not performed prior to the

appendix rupturing. The blog reported that the patient's recovery time was extended as it would have been one to three weeks had it been completed laparoscopically before the appendix ruptured, versus two to four weeks due to the surgery requiring the abdomen to be completely open.

One autistic individual did not discuss their specific experience with the ED, instead they discussed pain – and the lack of understanding of HCPs around hyper or hypo sensitivity can impact healthcare. Although this blog shared two examples when they accessed a dentist – the individual outlined ways for all HCPs to improve the experiences of individuals with ASD. This is pertinent to research question three and will be explored in more detail below.

Sensitivities

There were various items that were identified as a direct cause of overstimulation within the ED – the physical lights that illuminated the department, the various sounds a patient would hear, being physically touched, as well as pain. The barriers and associated recommendations are detailed below.

Barriers

Out of the six blogs considered, four did not identify specifically which component of the ED environment bothered them. Instead, the blogs generalized that it is the physical environment of the ED that can cause overstimulation, and that some HCP's are unclear of potential triggers that can escalate the feeling of being anxious or overstimulated. One autistic individual outlined the fact that they were already in a heightened emotional state before entering the ED: thus, being more sensitive to the environment around them. Three out of six blogs specified 'lights' as a sensitivity that contributed to overstimulation. All three of these blogs stated the lights were bright, with one stating it caused headaches. Out of six blogs, five

discussed the issue of sound; two specifically stated that the ED is too loud, one stated that trying to speak can be both physically and cognitively challenging when in a loud environment and the other two discussed potential solutions for either coping with the volume emitted or how to assist someone who has become non-verbal due to the environment. Touch was referenced once in one blog written by a caregiver stating the HCP's lack of understanding about the sensitivity to touch was making the patient feel uncomfortable. One autistic individual described pain as a barrier to accessing care as the main issue pertains to being either hyper or hypo sensitive to pain. They further outlined that brushing their teeth was painful, therefore needles were excruciating and recalled a situation where they nearly lost consciousness due to their perception that something was painful. One caregiver notes how their supported individual perceives pain differently than others and that ASD caused an abnormally high pain threshold for that individual, so when they complained that something hurt, it was exceptionally serious. Although this may be viewed as a communication concern, it is important to emphasize that everyone has different sensitivities – what one person views as painful, another may not. Therefore, various assessments and treatment options that would otherwise be considered routine (example: blood pressure readings) may inflict excruciating pain to someone with ASD.

Recommendations

One autistic individual offered the suggestion of being able to wait in the car if the waiting room is too busy. When it is their turn to be assessed/move into a room, they would be able to receive a text or a phone call summoning them back into the ED. Another individual suggested being able to dim the lights or having sunglasses to wear within the department. To combat the noise sensitivities, being able to use ear plugs or noise cancelling headphones. One autistic individual referenced a tool using the acronym 'check' which stands for communication,

health, environment, change and knowledge. Under the environment section, it recommends the

HCP check the environment for sensory issues, to ask the autistic individual about *their* sensory

preferences and what their sensitivities are and ascertain whether they are sensitive to touch.

This will allow for changes to occur to "minimize distress". In terms of pain, one blog suggested

the HCP's *ask* about pain tolerance when deciding which medication or anesthesia to use, but

also to ask the patient *how* they experience pain so that better care can be provided.

Communication

Barriers

Of the six blogs, five discussed issues with communication as a barrier to receiving care

discussing the expressive and comprehension issues of both individuals with ASD as well as the

HCP. Phrases such as "communication difficulties", "communication barriers", "communication

challenges", a lack of "clearly expressing or communicating" were used. Additionally,

generalized comments were made throughout the five blogs pertaining to communication as a

barrier to obtaining proper diagnosis and treatment within a timely manner. One highly

educated, autistic individual who works in a medical field, attempted to access care in an ED

"shut down" and transitioned from being able to communicate verbally to being non-verbal after

the HCP did not take her concerns seriously. A second individual with autism described how

their words "dissolve" when they transitioned between being verbal to non-verbal while

overstimulated.   One caregiver discussed how patients with ASD tried to communicate, however

multiple interactions caused overstimulation; the individual then refused to talk and left all

communication to the caregiver.

Recommendations

One blog author recommended the HCP ascertain if the autistic individual *can* communicate what is wrong or what brought them into the ED, if there are any communication needs or different methods of communicating effectively or if there are any adaptations required so both the patient and HCP are able to understand each other. One blog recommended "yes-or-no" questions to help if communication is difficult, or if the patient is non-verbal. Another blog recommended having "someone else" in the room or to write everything down. A second blog expanded on this and recommended the HCP being "clear" with their communication, to remain "specific" when asking about symptoms and to allow plenty of time for the autistic individual to process the information and then respond to the question asked. When a diagnosis or treatment is proposed, the blog author recommended the HCP explain the process and to be clear about the next steps.

Knowledge

Barriers

The knowledge of HCP's as it pertains to ASD was called into question within the blogs. One caregiver stated that the staff did not understand how the autistic individuals' sensitivities affected them and what could be done to make them more comfortable. This caregiver continued to describe how treatment would have been implemented earlier had ASD been more "thoroughly understood". One blog highlighted the assumption of some HCP's that once they have treated one individual with autism, the next patient will be similar: bringing the importance of training to the forefront of the discussion. Another outlined how proper training will allow the HCPs to realize that every step within the ED is a situation that the HCP has to either de-escalate the autistic individual to try and reduce anxiety and increase their comfort level; or it will escalate them and bring them closer to a meltdown. One blog stated that individuals with autism

are often "overwhelmed" before the HCP's are able to assess them; and the providers are unaware. This 'unawareness' traverses into not understanding things that could be "potentially triggering", which ultimately compromises their care. One blog states some individuals with autism and/or their caregivers will purposely refuse to disclose they are autistic due to previous "bad experiences" and the lack of "properly" understanding autism.

Recommendations

Four blogs discussed the impact of HCP training and knowledge – or lack thereof – and how it impacts their treatment. All four blogs discussed similar items, however in a slightly different context/phrasing. One blog stated that autism is a spectrum and one of the "biggest reasons" why proper training of HCP staff is so important, is so that treatment will reflect this diversity. This blog continued to state that a lack of training and a lack of resources will "likely escalate" the sensory state of the autistic individual and will ultimately move them towards a "meltdown" which renders treatment very difficult, if not "impossible". This sentiment was further discussed by a second blog which stated that if HCPs had more general training and awareness, they would be able to "adjust" their process to meet the needs of the patient. A third blog reiterated that the HCP knowledge and approach is the "most important factor" that needs to be considered when changes are made to the ED as it pertains to care of autistic patients as it is within this "face to face" interaction that will impact the positivity of the experience. Properly trained staff will allow them to "create comfortable environments" for autistic patients and will easily be able to shift towards personalized care and treatment. Effectively trained staff will allow patients with autism to feel "more confident" about sharing their diagnosis, thus increasing the quality of their care as the patient will understand they will be "properly understood".

Facilitators

Out of all six blogs, two discussed one facilitator – listening. In one blog, the autistic individual had a negative experience from a previous hospital and decided to seek a second opinion. In the second hospital, the individual described how the HCP *listened* to them like they had "all the time in the world". The HCP provided adequate pain relief and referred the individual to a specialist. That individual described the HCP as "patient", "attentive" and "kind". The second blog – written by a caregiver - stated that it is often the caregiver that has the best insight into what is normal for the autistic individual, alluding to the need for the HCP to *listen* to the caregiver.

Chapter 5. Discussion

Individuals with ASD often access healthcare more often than individuals who are neurotypical (Calleja et al, 2020) due to an increase in comorbidities. With this increase in healthcare utilization, it is important to understand how their experiences and barriers to accessing care relate to their diagnosis, as well as how it is similar- or different – to the previously published literature. This chapter discusses the results of the research as it pertains to the current literature. Due to the interconnectedness of the sensitivities, barriers/facilitators, and knowledge; this section will not be broken down into sections, but rather discussed as a whole.

As previously stated, the reason for seeking healthcare differs as widely as the individual with ASD. However, there is research that outlines the common overarching experiences of individuals with ASD seeking healthcare is negative. Weir et al (2022) published a study that indicated that the quality of healthcare is poorer for those with ASD compared to their neurotypical counterparts. Mason et al (2019) discussed how adults with ASD are "more likely to report unmet healthcare needs, and lower healthcare self-efficacy, compared to the general population" (p.3388). Walsh et al (2020) reiterated the unmet healthcare needs and correlated it to an increase in mortality. An example of this within the blogs was when one ASD patient did not receive an EEG to determine the cause of a seizure, and instead was discharged and instructed to follow up with an outpatient neurologist. Another example from the blogs is when one individual sought healthcare due to chest pain and vomiting blood, but instead of having the HCP listen to her story, determined the applicant had bulimia. A third example from the blogs is when the individual with ASD had stomach pain and was discharged home; only to return the next day with a ruptured appendix. This example could have been fatal had the individual not

returned to the hospital. With similar experiences outlined not only in the blogs, but also in

previously published literature, why is this community still experiencing substandard healthcare?

This study is not the only one to identify a variety of barriers to seeking healthcare.

Calleja et al (2020) completed a scoping review of 13 articles pertaining to barriers and enablers

and found that barriers to accessing healthcare for autistic adults included communication

difficulties, lack of knowledge about autism as well as the physical environment and sensory

sensitivities. Weir et al (2022) completed research on autistic adults and through self-reports, it

was noted that poor communication and sensory sensitivity were among a list of barriers to

accessing healthcare. Lipinski et al (2021) noted that even when trying to access mental health

services, they report a "therapists' lack of knowledge and expertise surrounding autism" (p. 1).

My research findings of communication, knowledge, and sensitivities as being common barriers

to healthcare align with the previously published research, as well as providing evidence that

ableism continues to exist within our healthcare system. The blogs outlined how the lack of

HCP knowledge on ASD has led to an increase in barriers as there is a lack of understanding that

the autistic individual is already entering an overstimulating environment in a heightened state,

that the physical environment is causing the individual to become overwhelmed, and that there is

an underlying communication challenge further complicating the situation.   However, with

previously published literature already identifying these concerns and barriers within the

healthcare system, why has nothing been done to change the policies or procedures within the

hospitals? Why has the environment of the ED not been altered to try and reduce the barriers?

While searching for appropriate blogs, one that did not meet the inclusion criteria,

although relevant – was written from the standpoint of HCP's. They discuss the importance of

properly trained staff "with the right tools, their care could make all the difference in delivering a

positive experience to those with autism" (IBCCES, 2020). This blog discusses the importance

of proper staff training to not only be able to manipulate the environment, provide better

communication tools and techniques, but also to reduce the stress and anxiety levels of the

patients to allow for proper assessments and treatment. This blog also discusses the financial

impact of having properly trained staff as the need to use sedating medication or restraints on

individuals with autism can be reduced. The ability to promote the hospital and ED as a

'certified autism center'; promoting the proper training and education of the HCPs to ensure

individualized care that is appropriate to the needs of the autism community will "help make

patient visits a more positive experience" (IBCCES, 2020). The blog concludes by stating:

"There's a growing need… It's ensuring you're meeting the needs of a segment of the

population" (IBCCES, 2020). Although this blog was written about a hospital within the United

States, is it possible to develop a certification process for ED's in Canada? Is it possible to add

ASD training, policies, and procedures into the already existing accreditation the hospitals need

to participate in?

Parallel Research

While the research I have been completing discusses the barriers ASD patients

experience while accessing healthcare, separate research has been conducted in the United

Kingdom to develop a framework that can be used to break down some of the barriers I

identified. Dr. Mary Doherty and her colleagues are members of Autistic Doctors International

(ADI) (Doherty et al, 2023); which is an organization of doctors and medical students who self-

identify as being autistic (ADI, 2024). The framework they developed is known as SPACE:

"Sensory needs, Predictability, Acceptance, Communication and Empathy" (Doherty et al, 2023,

p. 7). The goal of this framework was to help increase the accessibility of ASD patients by

providing accommodations, to reduce the inequities neurodiverse patients experience as well as to provide the healthcare providers a quick, easy to reference ways of making changes within the healthcare setting without overhauling the entire system. Although there are many salient points within the article, the fact that this research was conducted not only by doctors working in the healthcare system, but who are also autistic; and are not only able to view the inequities from both a healthcare provider and patient perspective but are also able to marry the challenges each community has into one relatable, easy to use solution is invaluable.

Limitations

There are a few limitations pertaining to this study. First, the author was the primary researcher and was the sole individual to complete the literature review, blog search, data synthesis and analysis. Although all efforts were taken to ensure no literature or blogs were missed, this is a possibility. There were a limited number of publicly available blogs to utilize in this study. While the information provided in the blogs was consistent with the literature, there is the possibility that there are others who had different experiences and could not be reflective of the entire population. There is also no way to verify exactly when the ED visit occurred in relation to the date on which the blog was written, therefore it is difficult to determine if recall bias could be a factor. However, the situation written about stood out to the blog author enough for them to write about their experiences for others to read and discuss. Another limitation is the fact that it is a small sample size and while there are multiple themes present within the blogs, it may or may not represent all the experiences of every autistic individual.

Recommendations for Future Research

There are numerous factors that will contribute to an individuals' experience in the emergency room– the staff, the time of day, support individuals present, the knowledge of the

care providers, the functional ability of the individual as well as any sensitivities they may possess. Blogs have been able to capture these experiences and contributing factors in a way that allows researchers to dissect their post to assess for any commonalities or shared phenomena. Looking at the blogs and comparing the results with the literature, the interconnectedness between the barriers and training cannot be ignored, nor should the potential solutions raised by the individuals impacted and affected by them. There needs to be more research on the current knowledge and skill level of HCP's as it pertains to ASD, but also how to properly educate and train them to provide individualized care. Research on how to alter the ED environment or providing assistive devices (such as noise cancelling headphones or sunglasses) and the impact on the experiences of the ASD individual is also warranted. Developing proper communication tools for those struggling to express their concerns, or for those who are non-verbal would also be beneficial. Making changes from a policy and procedure standpoint would benefit ASD patients as it would bring the onus back onto the healthcare system, rather than leaving it up to the HCPs to circumnavigate when an autistic individual is present at the ED.

Chapter 6: Conclusion

Nurses and doctors are required to go through school, write a qualifying examination and be licensed by a regulating body. However, with limited time in school, they are not able to learn everything about all illnesses and diseases. The lack of education and training for health care professionals is at the center of the barriers to accessing the ED. If staff were educated to the various sensory challenges individuals with ASD may have, then the healthcare staff should be able to question what supports, tools, or alterations are required. Moreover, they also may recognize the unique needs of individuals with ASD. Given that ASD is multifaceted in its presentation and symptoms; it is imperative that the healthcare professionals ensure that the care provided is individualized to meet their specific needs. The best way of doing that is to ask the patient – or support person if available.

When healthcare professionals are knowledgeable on ASD, patients may receive a more positive experience as they are able to accommodate the environment or procedure to help reduce anxiety and prevent escalation. Given the increase in individuals diagnosed with ASD, combined with their increased utilization of healthcare services, the need to ensure they are receiving appropriate, compassionate care is required. Being aware of the barriers this community faces, understanding there is a knowledge gap with the HCP's and not actively trying to make improvements is negligence. While more research on the various aspects of this situation is warranted, making immediate changes to easily adaptable areas (such as allowing the autistic adult to wait in a quiet room) will be the start of a greater shift within the healthcare system. It will allow this underserved community to see that their concerns have been heard and that steps are being initiated to make this crucial service more available to them.

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Appendix A

Athabasca University
RESEARCH CENTRE

CERTIFICATION OF ETHICAL APPROVAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: **25081**

Principal Investigator:
Mrs. Sabrina Brodofski, Graduate Student
Faculty of Health Disciplines\Master of Nursing

Supervisor/Project Team:
Dr. Gina Martin (Co-Supervisor)
Dr. Georgia Dewart (Co-Supervisor)

Project Title:
Autism Spectrum Disorder and the Emergency Department

Effective Date: January 25, 2023   **Expiry Date**:   January 24, 2024

Restrictions:

Any modification/amendment to the approved research must be submitted to the AUREB for approval prior to proceeding.

Any adverse event or incidental findings must be reported to the AUREB as soon as possible, for review.

Ethical approval is valid *for a period of one year*. An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

An Ethics Final Report must be submitted when the research is complete *(i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable))* or the research is terminated.

Approved by: **Date: January 25, 2023**

Barbara Wilson-Keates, Chair
Faculty of Health Disciplines, Departmental Ethics Review Committee

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