UNIVERSITÉ DU QUÉBEC À MONTRÉAL

EMERGENCY ROOM PSYCHIATRIC CONSULTATIONS: SOCIO-DEMOGRAPHIC AND CLINICAL DIFFERENCES BETWEEN CHILDREN WITH AND WITHOUT AUTISM SPECTRUM DISORDERS

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ESSAI

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COMME EXIGENCE PARTIELLE

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PAR

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DEDICATION

To my beautiful daughter, Giuliana, the light of my life; may you always follow your dreams and never give up; the opportunities are endless.

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LIST OF ABBREVIATIONS AND ACRONYMS

ASD Autism Spectrum Disorder

CGAS Children's Global Assessment Scale

ER Emergency room

MCH Montreal Children's hospital

NON-ASD Neurotypical

ABSTRACT

Recent years have witnessed an increase in pediatric emergency room (ER) visits for crisis mental health care in Canada and the United States, with a high proportion driven by youth with autism spectrum disorders (ASD). This study aims to characterize the socio-demographic and clinical profiles of autistic children presenting to an ER for crisis assessment, and compare them to those of neurotypical children also presenting to the ER in crisis. Twenty-five children with ASD and 286 without the disorder were compared in terms of age, sex, parent marital and socio-economic status, psychosocial functioning, suicidal behavior, psychiatric diagnosis and reasons for ER consultation. Results showed that children with ASD showed a higher frequency of male sex, younger age, increased suicidal behavior, less co-existing diagnosis of substance use disorder and greater prevalence of behavioral disorders as the reason for ER consultation. No differences in parental marital status, socio-economic status or psychosocial functioning were found. An understanding of the socio-demographic and clinical profiles of the autistic population will help clinicians identify the needs of this group seeking crisis intervention, improve management, orient service delivery, increase prevention and inform governmental organizations of the need to provide service accessibility.

Keywords: autism spectrum disorder, emergency room, psychiatry, crisis intervention.

RÉSUMÉ

Dans les dernières années, au Québec et aux États-Unis, les visites aux urgences pédiatriques pour des soins de santé mentale en situation de crise, ont connu une grande augmentation notamment pour les enfants ayant des troubles du spectre de l'autisme (TSA) Cette étude vise à caractériser les profils sociodémographiques et cliniques des visites à l'urgence des neurotypiques comparés à ceux ayant un trouble du spectre de l'autisme. Vingt-cinq enfants ayant un TSA et 286 enfants neurotypiques ont été comparés en termes d'âge, de sexe, de statut matrimonial et socio-économique des parents, de fonctionnement psychosocial, de suicidalité, de diagnostic psychiatrique et des motifs de consultation à l'urgence. Les résultats ont montré que les enfants autistes sont plus souvent de sexe masculin, sont plus jeunes, ont un comportement suicidaire plus marqué, présentent moins de diagnostics concomitants de troubles liés à l'utilisation de substances et présentent une plus grande prévalence de troubles du comportement en tant que motif de consultation aux urgences. Aucune différence n'a été constatée entre les deux groupes pour le statut matrimonial et socioéconomique des parents, ainsi que le fonctionnement psychosocial. Une meilleure compréhension des profils sociodémographiques et cliniques aidera les cliniciens à identifier les besoins des personnes ayant un TSA en situation de crise notamment pour améliorer la prise en charge, orienter la prestation des services, augmenter la prévention et informer les instances gouvernementales de la nécessité d'améliorer l'accessibilité aux services.

Mots clés : trouble du spectre de l'autisme, salle d'urgence, psychiatrie, intervention de crise.

INTRODUCTION

Recent years has witnessed a surge in pediatric emergency room (ER) visits by children in mental health crisis seeking immediate intervention in Canada and the United States (Leeb et al., 2020; Mapelli et al., 2015; Newton et al., 2016; Schlichting et al., 2017). In Canada, over one million youth are affected by mental illness (Mental Health Commission of Canada, 2022; Youth Mental Health Canada, 2019) and these numbers continue to escalate drastically (Centers for Disease Control and Prevention, 2020; Twenge et al., 2019).

Data from the Canadian Institute for Health Information (2020) described a 75% increase in ER visit rates for mental health disorders by Canadian youth aged 5 to 24 years between 2006-2007 and 2017–2018. Emergency room visits for mental health issues from March to October 2020 increased by 24% for youth ages 5 to 11, and 31% for those aged 12 to 17, compared to analogous data in 2019 (Leeb et al., 2020). This increase coincides with the scarcity of community-based mental health services, long waitlists, lack of continuity in resources (Heyland & Johnson, 2017) and service inaccessibility, such that youth present to the ER seeking psychiatric crisis care (Nordstrom et al., 2019).

Among patients visiting the ER for mental health issues, those diagnosed with autism spectrum disorder (ASD) have complex health care needs with frequent medical comorbidities (Dominick, 2019; Parker & Killian, 2020). Children with ASD often seek help from the ER for psychiatric disorders (Wu et al., 2015), frequently prompted by the shortage of intervention resources to support this population (Kalb et al., 2012). Given the increasing prevalence of ASD and of associated ER presentations, it behooves pediatric health care facilities to anticipate the needs of youth with ASD, including an awareness of their socio-demographic profiles and particularities of their clinical symptoms and presentations.

This essay is divided into three chapters. The first chapter will present a literature review on various sociodemographic and clinical characteristics of community youth with ASD and justifies the research objective. The second chapter presents the article accepted for scientific publication and contains the core results of the study and associated discussion. Lastly, the third chapter presents a general discussion of the essay, considering clinical implications and ending with a conclusion.

CHAPTER 1

DEFINITIONS AND LITTERATURE REVIEW

1.1 Autism Spectrum Disorder

According to the DSM-5, autism spectrum disorder (ASD) is a neurodevelopmental disability that is characterised as having persistent deficits in social communication and interaction across multiple social contexts, as well as restrictive and repetitive behaviors (American Psychiatric Association, 2013). Deficits in social-emotional reciprocity, in non-verbal communicative behaviors used for social interactions and in developing, maintaining, and understanding relationships are present. Etiology, phenotype, and outcomes of ASD are heterogeneous, and manifest as diverse deficits or impairments in behavioral features and communication (Masi et al., 2017). Severity is defined by three levels of support required for the individual (very substantial support, substantial support, or support). Restrictive repetitive patterns of behavior are manifest by at least two of the following behaviors: stereotypical or repetitive motor movements, use of objects or speech; insistence, inflexible adherence to routines, or ritualized verbal or nonverbal behaviors; highly restricted, fixated interests; and/or hyper or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. Symptoms must be present in the early developmental period in order to diagnose ASD (American Psychiatric Association, 2013; Centers for Disease Control and Prevention, 2022).

1.1.1 Prevalence of ASD in Youth

The current estimated prevalence of ASD in the United States among children and adolescents is 3.14% (Li et al., 2022), and rates have been increasing in the US, Canada, and other countries (Li et al., 2022; Maenner et al., 2020; Saini & Cox, 2020). A recent report by the Public Health Agency of Canada showed that 1 in 50 Canadian children (2.0%) aged 1-17 were diagnosed with ASD (Autism Alliance of Canada, 2022). Factors such as extensive screening at pediatrician visits (Kumar, 2021), increased public awareness (Campbell et al., 2011; King & Bearman, 2009; Kumar, 2021) and broadening criteria for diagnosis (Kumar, 2021; Neggers, 2014) may explain this increase in prevalence. Prevalence estimates in Quebec continue to rise from 15/10 000 (0.15%) in 2001 to 122/10 000 (1.2%) in 2015, consistent with national and global trends (Diallo et al., 2018).

1.2 Socio-Demographic and Clinical Characteristics of Children with ASD

The following is a summary of the socio-demographic and clinical characteristics of youth with ASD in the general population.

1.2.1 Sex

According to the Canadian Health Survey on Children and Youth, males are diagnosed with ASD approximately four times more frequently than females (Public Health Agency of Canada, 2022). This male predominance is consistent with findings of other epidemiological studies found in the literature (Fombonne, 2007). Similarly in Quebec, males predominate among those with ASD. Accordingly, 1 in every 41 males (2.4%) and 1 in every 153 females (0.7%) are diagnosed with ASD (male to female ratio approximately 4 to 1) (Public Health Agency of Canada, 2018).

Sex differences in terms of symptoms observed tend to resemble the sex differences observed in the general population. Males with ASD tend to display more externalizing behaviors such as aggression, hyperactivity and less prosocial behaviors (Mandy et al., 2012), while females tend to show more internalizing behaviors like depression, anxiety and emotional distress, to name a few (Mandy et al., 2012; Solomon et al., 2012). Researchers have postulated that externalized behaviors, typically observed in males, more readily prompt assessment and treatment among boys as they are more disruptive than the internalizing symptoms of girls (Werling & Geschwind, 2013).

1.2.2 Age

Globally, the current mean age at ASD diagnosis is 60.48 months, with a range of 30.90 - 234.57 months (van 't Hof et al., 2021). Although ASD can be diagnosed as early as 18 months of age (Hyman et al., 2020), the mean age of diagnosis for such youth is between 4 and 5 years of age (Baio, 2014). That being said, many children are not diagnosed before entry into the school system despite parental concerns that were flagged at an earlier age given the long waitlists for services (Chawarska et al., 2007; Heyland & Johnson, 2017; Zwaigenbaum et al., 2019).

In Canada, children aged 5 to 11 years of age had the highest prevalence rate of ASD (1 in 40) followed by youth aged 12 to 17 years old (1 in 53) and then those aged 1 to 4 years (1 in 91). The prevalence rate in the youngest age group was found to be much lower than the two older groups (Public Health Agency of Canada, 2022).

1.2.3 Parent Marital Status

Parents raising children with autism often face high levels of stress compared to families of neurotypical children (Estes et al., 2009; Hayes & Watson, 2013), however the literature on marital stability of parents with autistic youth shows mixed findings. On the one hand, higher divorce rates were reported for parents of children with ASD, compared to those without the diagnosis (Hartley et al., 2010). The increased level of mental health related concerns and lower relationship satisfaction were associated with divorce rates of these families, compared to those without an autistic child (Seltzer et al., 2011). Risdal and Singer (2004) conducted a meta-analysis of 13 studies investigating the effects of lifelong parenting on marital quality for parents of children with disabilities. Results showed higher divorce and marital discord compared to parents of children without a disability. By contrast, Freedman et al. (2012) collected data on 77,911 parents of children ages 3-17, of whom 913 had a child with ASD. Findings showed that parents of youth with versus without ASD are equally likely to remain coupled.

1.2.4 Socio-Economic Status

Socio-economic status (SES) is a measure that looks at one's economic and social position in relation to others, based on income, education and occupation. Typically, SES is divided into three levels (high, medium and low) (Worthy et al., 2020). Research has shown that socio-economic status (SES) is a key factor influencing quality of life for youth and families (American Psychological Association, 2010). In fact, links exist between low SES and negative psychological outcomes (American Psychological Association, 2010), such as higher levels of emotional and behavioral/social difficulties, delinquent behaviors and attention deficit hyperactivity disorder among adolescents (DeCarlo Santiago et al., 2011; Russell et al., 2016; Spencer et al., 2002).

There is also evidence of an association between mental illness and social deprivation in the general population (Marmot, 2012; Wilkinson & Marmot, 2003), which is even greater for those with neurodevelopmental disorders and comorbid psychiatric issues (Nicholson & Hotchin, 2015). Socioeconomic factors, such as family income and education play an important role in how families cope with children's disabilities (Arim et al., 2016), which is particularly true with respect to those with ASD who are known to live in more deprived areas than the general population (Delobel-Ayoub et al., 2015). Children from such low-income families have less access to acute care, specialized services, educational services, and community services compared to those who came from higher income families (Smith et al., 2020). In one study by Delobel-Ayoub et al. (2015), the SES of 500 children with ASD and 245 children with

severe intellectual disability was measured. Results showed that the prevalence of ASD with associated intellectual disability was highest in areas with the greatest deprivation including the highest level of unemployment, individuals with no diplomas, single parent families and immigrants.

An inverse correlation of lower SES and higher prevalence of ASD was found in Canada, where the prevalence of ASD was highest in households with the lowest income, and lowest in the highest income households (Public Health Agency of Canada, 2022). Yet, other studies did not show that same inverse correlation. For instance, some studies have shown a link between higher income and higher ASD prevalence (Yu et al., 2021), while others do not demonstrate any association (Larsson et al., 2005). These disparate findings are worthy of reconciliation, and perhaps suggest heterogeneity among populations studied.

1.2.5 Psychosocial Functioning

Psychosocial functioning of youth consists of both their psychological development and their interaction with the social environment (Arim et al., 2015). The Children's Global Assessment Scale (CGAS) is one of the most widely used measures of assessing overall functioning and severity of impairment in children ages 4-18 years of age (Shaffer et al. 1983). Children with ASD have been found to have lower psychosocial functioning than peers without the diagnosis (Arim et al., 2015; Joshi et al., 2010; Pathak et al., 2019; Public Health Agency of Canada, 2022; Tillmann et al., 2019). Moreover, Canadian youth with ASD aged 12-17 were found to be less happy and satisfied with life overall compared to their neurotypical peers. A statistically significant difference was found between the two groups, with 80.7 % of ASD reporting to be "very satisfied" or "satisfied" compared to 90.9% of those without ASD. Similarly, 45.1% of those with ASD report being "happy and interested in life" compared to 64.7% of their neurotypical peers (Public Health Agency of Canada, 2022).

1.2.6 Suicidal behavior

Suicide is the second leading cause of death for youth aged 10-19 (Centers for Disease Control and Prevention, 2019). Individuals with ASD are at a higher risk of suicidal behavior (i.e. suicide ideation and attempts) than those without the disorder (Bardon et al., 2015; Kõlves et al., 2021; Rybczynski et al., 2022; Zahid & Upthegrove, 2017). Youth with ASD are twice as likely to report suicidal thoughts (Rybczynski et al., 2022), six times as likely to attempt suicide (Chen et al., 2017) and twice more likely to die by suicide (Kirby et al., 2019) at a much younger age compared to their peers without the disorder (O'Halloran et al., 2022). Moreover, suicidal risk is high in those with ASD, particularly given their poor communication skills, feelings

of social isolation, lack of emotional connectedness to others, and higher risk of being bullied compared to those without the disorder (Fleming, 2022; Maïano et al., 2015).

1.2.7 Psychiatric Diagnosis

Youth with neurodevelopmental disabilities have been found to have an increased vulnerability to physiological, psychological, social, economic, and environmental factors related to mental health issues and tend to manifest their emotional distress differently than typically developing children (Esposito et al., 2011; Lunsky, 2004). Research by Joshi et al. (2010) demonstrated that autistic youth exhibit elevated levels of psychiatric comorbidity and dysfunction comparable to the referred population of youth without ASD. Findings showed that 95% of youth with ASD had 3 or more co-existing psychiatric disorders, and 74% had 5 or more comorbid disorders. Youth with ASD were also found to be more functionally impaired and needed more therapeutic interventions and school support than age and sex matched youth without an ASD diagnosis. In addition, autistic youth have a high prevalence of comorbidity with behavioral problems and externalizing disorders and increased psychiatric comorbidity with disorders such as anxiety and depression (Diallo et al., 2018; Kirsch et al., 2020; McCarthy, 2007).

Characteristics of ASD such as poor social functioning, emotional lability and fixed habits of behavior tend to resemble symptoms of other mental health disorders such as bipolar, mood, anxiety and schizophrenia spectrum disorders (Joshi et al., 2013). These symptoms and co-existing psychiatric disorders are also commonly found in those with substance use disorders (SUD) (Jané-Llopis & Matytsina, 2006). In a recent cohort study of 6,599 individuals with ASD, and 26,296 without the disorder, those with ASD were at an increased risk of having a SUD, and the risk was greater in those with behavioral comorbidities and who were not being treated with psychotropic medication. The mortality risk was greater for those with ASD and a co-existing SUD than those without ASD, with or without an SUD (Huang et al., 2021).

On the contrary, a systematic review of studies focusing on co-existing ASD and SUD found that rates of SUD were generally lower in those with ASD compared to those without (Arnevik & Helverschou, 2016). This low rate of co-existence may be caused by limited social contacts, reducing the influences of peers, and leaving the autistic youth to the constraints imposed by their tendency to literally interpret social rules (Ramos et al., 2013). As such, those with ASD may be less likely to break rules or engage in risky behaviors such as drug experimentation.

1.2.8 Reasons for ER Consultation

The emergency room psychiatry department often care for children with neurodevelopmental disorders and those with mental health emergencies, particularly when their pediatricians are not readily accessible (Lin, 2012). In Canada, and specifically Quebec, given the shortage of community-based health care services, many families instead seek mental health care from already overburdened emergency care (Feith, 2022).

Psychiatric illness and mental health concerns are common reasons for ER consultation among autistic youth (Beverly et al., 2021; Kalb et al., 2012; Kogan et al., 2008), who are 9 times more likely to visit the ER than those without the disorder. Youth with ASD are more likely than their peers without to present to the ER for externalizing disorders (Lytle et al., 2018) with behaviors such as physical aggression, disruptive behaviors, self-harm and running away as primary reasons (Kalb et al., 2012).—In addition, autistic youth are also known to have a high prevalence of medical problems such as anxiety, sleep disturbance, recurrent infections, including those of the gastrointestinal tract, seizures, and epilepsy (Frye, 2015), to name a few, all of which can also present with behavior dysregulation (Frye, 2015; Wu et al., 2015). Thus, autistic children and their families often seek help from the ER for crisis intervention, given the high frequency of underlying medical problems presenting as behavior dysregulation.

The psychosocial functioning of youth who present to the ER has also been documented in the literature. In one study by Biros et al. (2008), it was found that 20% of pediatric patients had moderate to severe depressive symptoms, and only 50% of their caregivers recognized their child's depression. Findings suggest that the ER can serve to assist in the preliminary screening of pediatric patients at risk for psychosocial impairment (Montaño et al., 2011). Furthermore, researchers comparing reasons for ER utilization among youth with and without ASD found that approximately 14,000 of the four million reviewed cases were youth with ASD, and that 13% of these youth presented to the ER for psychiatric consultation, compared to less than 2% of children without the diagnosis. The ER visits were often prompted by a lack of community support, particularly a shortage of resources to support autistic children and their families (Kalb et al., 2012).

Emergency departments are a crucial point of suicide-related care (Cervantes et al., 2023). Cervantes et al. (2023) used the National Emergency Department sample databases to explore discrepancies in prevalence of ER visits with suicide ideation and self-harm behavior by youth with ASD, ID and those without these

diagnoses. Findings showed greater ER visits for suicide ideation or self-harm in youth with ASD (5.1%) and those with ID (6.6%) than youth without either condition (1.2%).

1.3 Emergency Rooms in Quebec

The literature suggests that obstacles to accessing services within the health care system are typically reasons for disproportionate use of the ER for mental health urgencies (Fleury et al., 2019; Nesper et al., 2016). These often include difficulty accessing outpatient services and resources within the community, insufficient funding, as well as servicing gaps in terms of availability (Gaynes et al., 2015; Moroz et al., 2020). Furthermore, the decreasing availability of mental health services results in increased ER visits and length of stay (Nesper et al., 2016). In Quebec, and especially in Montreal, overcrowded pediatric emergency rooms has become a "historic crisis" as physical space for patients becomes more limited and staff shortages continue to rise (Watts, 2022).

1.4 Services for ASD in Quebec

The increasing prevalence of autistic youth, with Montreal being the highest in the province (Diallo et al., 2018), has consequently increased the number of referrals for both diagnostic and intervention services in Quebec. Evidently, this raises great concerns regarding the availability of these services (Zeidan et al., 2019). Given the scarcity of community-based mental health care services, many families instead seek help from already overburdened emergency care (Feith, 2022).

1.5 Study Objective

The existing literature describes the socio-demographic and clinical characteristics of youth with ASD as they present in the community, however, less is known about a subset of this group who present to a metropolitan pediatric ER in crisis. This doctoral essay aims to compare autistic youth in crisis with neurotypical youth that present to a Montreal ER for crisis intervention.

1.5.1 Research Question

Are there significant differences between youth with ASD and neurotypical youth who present to the ER in crisis in terms of sex, age, parent marital status, socio-economic status, psychosocial functioning, suicidal behavior, psychiatric diagnosis and reasons for ER consultation?

Gaining this knowledge will help emergency care professionals tailor their support and interventions of this population going forward, in order to better service autistic youth in the ER, post discharge as well as

in the community. In addition, gaining a better understanding of these profiles will serve to inform government agencies and policy makers of the urgency to make services more available and accessible to this vulnerable population.

CHAPTER 2

EMERGENCY ROOM PSYCHIATRIC CONSULTATIONS; SOCIO-DEMOGRAPHIC AND CLINICAL DIFFERENCES BETWEEN CHILDREN WITH AND WITHOUT AUTISM SPECTRUM DISORDERS

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The emergency room (ER) often serves as the first point of care for children with mental health emergencies in need of crisis intervention (Leeb et al., 2020; Schlichting et al., 2017). In recent years, there has been a considerable increase in ER visits by children for crisis mental health care in Canada and the United States (Burstein et al., 2019; Dolan et al., 2011; Mapelli et al., 2015; Newton et al., 2016; Sills & Bland, 2002). Studies detailed in a recent review by Hoge et al. (2022) found annual increases in ER utilization for mental health consultation of 6 to 10% per year, greatly exceeding pediatric ER visits for non-mental health reasons. Current data from the Canadian Institute for Health Information (2020) described a 75% increase in ER visit rates for mental health disorders by Canadian youth aged 5 to 24 between 2006-2007 and 2017–2018. This increasing rate coincides with North American trends of scarce community-based mental health services, long waitlists, and a lack of continuity in resources (Halmer et al., 2015; Heyland & Johnson, 2017; Kalb et al., 2012).

Among patients visiting the ER for mental health issues, those diagnosed with autism spectrum disorder (ASD) have complex health care needs with frequent medical comorbidities (Dominick, 2019; Parker & Killian, 2020), and are among the most frequent users of the ER (Wu et al., 2015). Autism spectrum disorder is a developmental condition that affects an individual's behavior and communication (American Psychiatric Association, 2013). The number of children diagnosed with ASD continues to rise, with the most recent prevalence at 1 in 36 youth (Maenner et. al., 2023). In Canada, the prevalence of ASD in youth has also increased substantially over the last decade (Saini & Cox, 2020). A recent report by the Public Health Agency of Canada showed that 1 in 50 children (2.0%) 1-17 years of age were diagnosed with ASD (Autism Alliance of Canada, 2022).

2.1.1 Sex

According to the Canadian Health Survey on Children and Youth, males are diagnosed with ASD approximately four times more frequently than females (Public Health Agency of Canada, 2022). Similarly in Québec, the majority is in males. Recent data shows that 1 in every 41 males (2.4 %) and 1 in every 153 females (0.7 %) are diagnosed with ASD (male to female ratio approximately 4 to 1) (Public Health Agency of Canada, 2018). Sex differences in terms of symptoms observed tend to resemble the sex differences observed in the general population. Males with ASD tend to display more externalizing behaviors such as aggression, hyperactivity and less prosocial behaviors (Mandy et al., 2012), whereas females tend to show more internalizing behaviors like depression, anxiety and other emotional symptomatology, to name a few (Mandy et al., 2012; Solomon et al., 2012).

2.1.2 Age

Globally, the current mean age at ASD diagnosis is 60.48 months, with a range of 30.90 - 234.57 months (van 't Hof et al., 2021). In Canada, the median age at diagnosis for ASD was 3.7, and more than half of youth were diagnosed with ASD before the age of 5. Over 40% received an ASD diagnosis between the ages of 5-11 years of age, and approximately 6% were between 12-17 years old (Public Health Agency of Canada, 2022).

2.1.3 Parent Marital Status

The marital stability of parents with autistic youth shows mixed findings. On the one hand, higher divorce rates were reported for parents of children with ASD, compared to those without the diagnosis (Bahri et al., 2023; Hartley et al., 2010). Bahri et al. (2023) found that the risk of divorce in families of children with autism remains high through childhood into early adulthood, with 36% of those with autism in their sample experiencing a parental divorce by age 30. By contrast, other studies found that having an autistic child does not lead to higher parental divorce (Baeza-Velasco et al., 2013; Freedman et al., 2012). Freedman et al. (2012) collected information on 77,911 parents of children aged 3-17, of whom 913 had a child with ASD. Results showed that parents of youth with ASD, compared to those without, are equally likely to remain coupled, while others have found comparable divorce rates between the two (Namkung et al., 2015).

2.1.4 Socio-Economic Status

The literature reflects mixed findings on the relationship between socio-economic status (SES) and children with ASD. Children from low-income families have less access to acute care, specialized services, educational services, and community-based services compared to those who come from higher-income families (Smith et al., 2020). An inverse correlation of lower SES and higher prevalence of ASD was found in Canada, where the prevalence of ASD was highest in households with the lowest income, and lowest in the highest income households (Public Health Agency of Canada, 2022). Thus, family SES may indirectly translate in a greater likelihood and timeliness of a formal ASD diagnosis given that this process is often facilitated by factors such as parental education and awareness, self-advocacy, access to private sector resources and social support. Yet other studies did not show the same inverse correlation. For instance, some studies have shown a link between higher SES and higher ASD prevalence (Durkin et al., 2010; Fountain et al., 2011; Thomas et al., 2012; Yu et al, 2021), while others did not demonstrate any association

(Larsson et al., 2005; Sun et al., 2014). These disparate findings are worthy of reconciliation, and perhaps suggest heterogeneity among populations studied.

2.1.5 Psychosocial functioning

The psychosocial functioning of those with ASD has been found to be lower than peers without the diagnosis (Arim et al., 2015; Joshi et al., 2010; Pathak et al., 2019; Public Health Agency of Canada, 2022; Tillmann et al., 2019). Canadian youth with ASD aged 12-17 were found to be less happy and satisfied with life overall compared to their neurotypical peers. A statistically significant difference was found between the two groups, with 80.7% of ASD reporting to be "very satisfied" or "satisfied" compared to 90.9% of those without ASD. Similarly, only 45.1% of those with ASD report being "happy and interested in life" compared to 64.7% of their neurotypical peers (Public Health Agency of Canada, 2022).

2.1.6 Suicidal Behavior

Suicide is the second leading cause of death for youth aged 10-19 (Centers for Disease Control and Prevention, 2019). Individuals with ASD are at a higher risk of suicidal behavior (i.e. suicide ideation and attempts) than those without the disorder (Kõlves, et al., 2021; Rybczynski et al., 2021; Zahid & Upthegrove, 2017). In a systematic review of studies that investigated suicidal behavior in ASD, the risk of ideation and attempts in those with the disorder was higher compared to those without, with an odds ratio of 1.7 (Zahid & Upthegrove, 2017). Bardon et al. (2015) also suggest that suicidal behaviors are present in individuals with ASD, even if the completion of suicide is less prominent than in the general population. Moreover, the risk of suicidal behaviors is high in those with ASD, particularly given their poor communication skills, feelings of social isolation, lack of emotional connectedness to others, and higher risk of bullying compared to those without the disorder (Fleming, 2022; Maïano et al., 2016).

2.1.7 Psychiatric Diagnosis

Children with neurodevelopmental disabilities have been found to be more vulnerable to physiological, psychological, social, economic, and environmental factors related to mental health issues and suicide risk, and tend to manifest their emotional distress differently than typically developing children (Esposito et al., 2011). Those with ASD were found to have a high prevalence of both externalizing and behavioral problems (McCarthy, 2007). Hossain et al. (2020) conducted an umbrella review to summarize the current evidence of psychiatric comorbidity among those with ASD. Their study included 14 systematic reviews

and 12 meta-analyses. Findings showed a high prevalence of comorbid psychiatric disorders amongst diverse age groups, with a majority in younger participants. Moreover, research by Joshi et al. (2010) demonstrated that youth with ASD using psychiatric services exhibit elevated levels of psychiatric comorbidity and dysfunction comparable to the referred population of youth without ASD. Findings showed that 95% of these youth with ASD had 3 or more co-existing psychiatric disorders, and 74% had 5 or more comorbid disorders. These youth with ASD were also found to be more functionally impaired and needed more therapeutic interventions and school support than age and sex-matched youth without an ASD diagnosis. Despite the high risk of developing mental health issues in children with ASD, there is still a tendency to underdiagnose psychiatric disorders in this population (Levy et al., 2010; Rossetti, 2020).

2.1.8 Reasons for ER Consultation

Emergency room professionals often care for youth with neurodevelopmental disabilities and those with mental health emergencies, particularly when their pediatricians are not readily accessible (Lin, 2012). In Canada, and specifically Québec, given the shortage of community-based health care services, many families instead seek care from already overburdened emergency care (Feith, 2022). Psychiatric illness was identified as one of the most common reasons for youth with ASD to visit the ER (Beverly et al., 2021; Kalb et al., 2012; Kogan et al., 2008), and are 9 times more likely to visit than youth without the disorder. Weiss

et al. (2018) found that transitioning youth were more likely to visit the ER for psychiatric reasons and to have at least one comorbid psychiatric disorder compared to their peers without the disorder. In addition, autistic youth are also more likely to present to the ER for externalizing disorders than their peers without ASD (Lytle et al., 2018), with behaviors such as physical aggression, disruptive behaviors, self-harm and elopement as primary reasons for ER visits (Kalb et al., 2012). Given the extreme vulnerability of this population, youth with ASD were found to access the ER for emotional and behavioral difficulties 4 times more often than those without ASD (Liu et al., 2017).

2.2 ASD in the ER

A wide spectrum of disruptive behavioral manifestations is associated with ASD, including irritability, social withdrawal, hyperactivity, tantrums, aggression, self-injury and anxiety (Frye, 2015). In addition, youth with ASD are also known to have a high prevalence of medical problems such as recurrent infections, including those of the gastrointestinal tract (GI), seizures and epilepsy (Frye, 2015), all of which can also present with behavior dysregulation (Wu et al., 2015; Frye, 2015). As a result, those with ASD and their

families often seek help from the ER for crisis intervention (Wu et al., 2015), given the high frequency of behavior dysregulation often associated with the disorder (Frye, 2015). Researchers comparing reasons for ER utilization among children with and without ASD found that approximately 14,000 of the four million reviewed cases were autistic youth, and that 13% of youth with ASD presented to the ER for psychiatric consultation, compared to less than 2% of children without the diagnosis. The ER visits were often prompted by a lack of community support, particularly a shortage of resources to support autistic children and their families (Kalb et al., 2012). Given the current increased prevalence of ASD and associated ER presentations, it behooves health care facilities to anticipate the needs of those with ASD and of their families, which includes an awareness of their socio-demographics and the particularities of their clinical symptoms and presentations.

Ample literature exists on the socio-demographic and clinical profiles of youth with ASD in the community, however, less is known about a subset of this group who present to a metropolitan pediatric ER in crisis. This study aims to compare autistic children in crisis with typically developing children who present to the ER for crisis intervention. The two groups are compared in terms of sex, age, parent marital status, socio-economic status, psychosocial functioning, suicidal behavior, psychiatric diagnosis and reasons for ER consultation.

2.3 Method

2.3.1 Participants

This secondary analysis was conducted on 311 participants (115 males, 188 females, 8 n/a) between the ages of 5 and 18 (M = 14.1; SD = 2.3) who were included in an ongoing gene-environment study on suicide being conducted at the Montreal Children's Hospital. The main focus of the gene-environment study was to investigate the role of genetics in suicidality, and specifically borderline personality disorder, in hopes of furthering science regarding the genetic underpinnings of these conditions and thus potentially promoting early intervention. All variables in the two studies were identical (i.e. clinical, sociodemographic and genetic sampling). However, for purposes of this study focusing on the ASD population, we only selected data harvested from the medical charts and pertinent to our research. Inclusion criteria to participate in the current study included the following: (1) being between 5 and 18 years of age, (2) having been a patient at the Montreal Children's Hospital ER and evaluated by an ER psychiatrist at least one time between the years 2013 and 2019, (3) having partaken in the gene-environment study on suicide

conducted at the Montreal Children's Hospital, and (4) having a diagnosis of ASD to be included in the ASD group.

2.3.2 Procedure

In conformance with the ethical principles outlined in the policies and procedures for conducting research at the Montreal Children's Hospital, this research adheres to the objectives pertaining to the respect and well-being of an individual (McGill University Health Center, 2017). A research protocol was presented to the hospital's ethics committee and research approval was obtained. Patients who presented to the hospital's ER for crisis intervention were asked to participate in the gene-environment study by a research assistant, following a psychiatric assessment by the Mental Health Emergency Team. Recruitment took place between the years 2013 and 2019, with the majority of participants recruited within the first two years. Research assistants were trained by the research coordinator of the team, and underwent two mandatory training sessions offered by the McGill University Health Center Research Institute to ensure conformity to research design and conduct and ethical standards by those involved in the research project.

For the current study, medical charts were reviewed and socio-demographic and clinical information pertinent to the present research was extracted, coded and entered into a data chart. Research assistants helped cull information and enter data. Participants were coded and identifying information was removed to maintain confidentiality. An ASD diagnosis was pre-determined by a number of clinicians including neuropsychologists and psychiatrists.

These diagnoses were officially recorded in the patient's chart prior to their ER arrival. The vast majority were evaluated by a neuropsychologist and administered the Autism Diagnostic Observation Schedule (ADOS), a semi-structured, standardized test for the diagnosis of ASD based on DSM-IV, DSM-5, and ICD-10 diagnostic criteria (Lim et al., 2018). Those with an ASD diagnosis already presented in their charts were identified, allocated a numeric code and assigned to the ASD group for the purposes of this study, while the remaining participants constituted the Non-ASD group.

2.3.3 Measures

2.3.3.1 Patient medical chart

A medical chart review was conducted on data previously obtained from participants who agreed to participate in a gene-environment study on suicide conducted at the Montreal Children's Hospital. Medical

charts were thoroughly reviewed and used to ascertain all pertinent socio-demographic and clinical information, as well as to determine which patients were diagnosed with ASD.

2.3.3.2 Data sheet

Socio-demographic and clinical information from the sample including age, sex, socioeconomic status, parental and family data, patients' medical and psychiatric history, suicidal behavior, psychosocial functioning and reasons for ER presentation was collected and incorporated into an Excel chart. The data sheet was developed to facilitate group comparisons.

2.3.3.3 The Children's Global Assessment Scale

The Children's Global Assessment Scale (CGAS) is one of the most widely used measures of overall functioning and severity of impairment in children. It is a global measure of both social and psychiatric functioning for children ages 4–18 years of age (Shaffer et al., 1983). The CGAS is a single rating scale with a range of scores from 1 to 100, designed primarily to be used by clinicians. Anchors at 10-point intervals include descriptors of functioning and psychopathology for each interval. Raters' score is based on the child's social and symptomatic functioning, with 1 being most impaired to 100 being healthiest, and 70 representing normal functioning (Shaffer et al., 2000). The CGAS score is typically compiled using interview information on the patient's academic and recreational performance, psychiatric impairment, family functioning, substance use and involvement with the law (Shaffer et al., 1983).

Both reliability and validity have been reasonably established in research settings. Joint reliability when tested in research settings was found to be high (from 0.83 to 0.91) and when tested in clinical settings, moderate agreement had been demonstrated (from 0.53 to 0.66). Test-retest reliability was also found to be high (0.85) (Shaffer et al., 2000). In addition, data obtained on the CGAS during a pilot study in Puerto Rico demonstrate high interrater reliability and both concurrent and discriminant validity (Bird et al., 1987).

2.3.4 Data analysis

This study is one that is comparative and quantitative in nature. Group means were determined, and scores between ASD and Non-ASD groups were compared. Two types of analyses were conducted on the collected data. First, independent group t-tests were conducted to compare the median age of participants in the ASD and Non-ASD groups. Second, chi-square tests were conducted to compare inter-group differences in sex, parent marital status, socio-economic status, psychosocial functioning, suicidal behavior,

psychiatric diagnoses and reasons for ER consultation. An alpha level of .05 was used for all statistical tests. All analyses were conducted using Excel 2016 and SPSS version 26.0.

2.4 Results

Data on 311 participants was obtained. Twenty-five participants with a diagnosis of ASD constituted the ASD group and the remaining 286 participants without the diagnosis made up the Non-ASD group. When comparing ASD and Non-ASD groups, a statistically significant difference was found for sex, X^2 (1, N = 303) = 11.97, p < .001 with a small effect size ($\phi = 0.20$). Over half of the ASD group who sought crisis intervention were males (17 males: 7 females) demonstrating a greater frequency of males with ASD who present to the ER compared to those without the condition (73% of ASD group vs. 35% of Non-ASD group). A statistically significant inter-group difference was found for age, t(303) = -3.08, p = .002 with a medium effect size (d=-0.66). That is, younger children were more likely to present to the ER compared to those without the diagnosis. When comparing group differences in parent marital status, results were not clinically significant X^2 (1, X = 293) = .000 Y = .986 and demonstrated a very small effect size (Y = 0.001). There were no statistically significant inter-group differences with respect to SES, Y = 0.001 = 1.39 Y = .512 with a small effect size (Y = 0.001). Results also showed no significant differences in terms of overall psychosocial functioning between youth with ASD and those without when presenting to the ER, Y = 0.001 = 0.009 Y = 0.

In our analysis of suicidal behavior (which included suicidal ideation, suicide attempt, suicidal with a plan and hospitalization), we performed two comparisons, as there was uncertainty in our data whether the 'n/a' category (Table 1) reflected suicidal or non-suicidal participants. First, we compared the two groups on suicidal behavior, excluding the 'n/a' category from our analysis, assuming that the participants for whom the 'n/a' category was recorded were all non-suicidal (withdrawing them from the numerator and denominator). Results indicated a significant inter-group difference, X^2 (4, N = 261) = 14.99 p = <.005 and demonstrated a small effect size ($\phi = 0.24$). In the second comparison, we assumed that those for whom the 'n/a' category was recorded were all suicidal and added them to the numerator and denominator for both groups (ASD: 19/25 vs. Non-ASD: 182/286). Results again showed a statistically significant inter-group difference, X^2 (5, N = 311) = 16.02 p = .007 and demonstrated a small effect size ($\phi = 0.23$). Thus, in both comparisons, the ratio for suicidality is higher for the ASD than the Non-ASD population. However, as we could not discern whether the unknown group ('n/a' category in Table 1) represented suicidal or not suicidal youth, and thus to avoid ambiguity and to be conservative, they have been excluded from our final

analysis. Chi-squared test results associated with categorical variables (sex, parent marital status, socioeconomic status (SES), psychosocial functioning and suicidal behavior) and a t-test result for the continuous variable (age) are presented in Table 1.

Table 1 Socio-demographic and clinical characteristics per participant sample

Characteristics	Neurotypical (NonASD) N = 286	Autistic (ASD) N = 25	X ²	t	р	φ	d
Sex, n(%)			11.96		<.001*	.20	
Male	98 (34.3)	17 (68.0)					
Female	181 (63.3)	7 (28.0)					
n/a	7 (2.4)	1 (4.0)					
Age, n(%)				-3.08	.012*		2.22
5-9	11 (3.8)	4 (16.0)					
10-14	121 (42.3)	12 (48.0)					
15-17	149 (52.1)	8 (32.0)					
n/a	5 (1.8)	1 (4.0)					
Parent marital stat., n(%)			.000		.986	.001	
Intact – 2 parents	135 (47.2)	12 (48.0)					
Single	134 (46.9)	12 (48.0)					
n/a	17 (5.9)	6 (24.0)					
SES, n(%)			1.34		.512	.07	
High	15 (5.2)	0 (0.0)					
Middle	156 (54.6)	12 (48.0)					
Low	77 (26.9)	7 (28.0)					
n/a	38 (13.3)	6 (24.0)					
Psych functioning, n(%)			6.09		.193	.15	
CGAS below 40	19 (6.7)	3 (12.0)					
CGAS 40-49	73 (25.5)	11 (44.0)					
CGAS 50-59	126 (44.1)	7 (28.0)					
CGAS 60-69	25 (8.7)	1 (4.0)					
CGAS 70 and above	4 (1.4)	0 (0.0)					
n/a	39 (13.6)	3 (12)					
Suicidal behavior, n(%)			14.99		.005*	.24	
Not suicidal	104 (36.4)	6 (24.0)					
Suicidal	139 (48.6)	12 (48.0)					
n/a	43 (15.0)	7 (28.0)					

^{*} p<.05

When comparing group differences on psychiatric diagnoses, results showed a significant difference between the ASD and Non-ASD groups on a co-existing diagnosis of substance use disorder (SUD), X^2 (1, N = 303) = 3.91 p = .048 with a small effect size (ϕ = 0.11). Thus, substance use disorder was less prevalent among youth with ASD compared to those without presenting to the ER in crisis. Results for each psychiatric disorder are presented in Table 2.

Table 2 Psychiatric Diagnoses per participant

Characteristics	Neurotypical (Non-ASD)	Autistic (ASD)	X ²	р	φ
	N = 286	N = 25			
Mood disorder, n(%)			1.28	.258	.065
Without	218 (76.2)	22 (88.0)			
With	60 (21.0)	3 (12.0)			
n/a	8 (2.8)	0 (0.0)			
Anxiety disorder, n(%)			0.41	.522	.037
Without	195 (68.2)	19 (76.0)			
With	84 (29.4)	6 (24.0)			
n/a	7 (2.4)	0 (0.0)			
Personal. disorder, n(%)			2.02	.155	.082
Without	258 (90.2)	25 (100.0)			
With	21 (7.3)	0 (0.0)			
n/a	7 (2.4)	0 (0.0)			
Eating disorder, n(%)			2.36	.127	.088
Without	255 (89.2)	25 (100.0)			
With	24 (8.4)	0 (0.0)			
n/a	7 (2.4)	0 (0.0)			
Behavior disorder, n(%)	, ,	, ,	0.46	.498	.039
Without	219 (76.6)	21 (84.0)			
With	61 (21.3)	4 (16.0)			
n/a	6 (2.1)	0 (0.0)			
Adhd/LD disorder, n(%)			0.31	.577	.032
Without	174 (60.9)	17 (68.0)			
With	105 (36.7)	8 (32.0)			
n/a	7 (2.4)	0 (0.0)			
Attachment dis., n(%)			0.58	.447	.044
Without	274 (95.8)	24 (96.0)			
With	5 (17.5)	1 (4.0)			
n/a	7 (2.4)	0 (0.0)			
Adjustment dis, n(%)			1.48	.223	.070
Without	154 (53.8)	17 (68.0)			
With	124 (43.4)	8 (32.0)			
n/a	8 (2.8)	0 (0.0)			
Parent-child rel. dis., n(%)	, ,	. ,	0.82	.364	.052
Without	212 (74.1)	21 (84.0)			
With	67 (23.5)	4 (16.0)			
n/a	7 (2.4)	0 (0.0)			

Substance use dis, n(%)			3.91	.048*	.114
Without	240 (83.9)	25 (100.0)			
With	38 (13.3)	0 (0.0)			
n/a	8 (2.8)	0 (0.0)			
Other disorders, n(%)			1.26	.261	.064
Without	219 (76.7)	22 (88.0)			
With	60 (20.9)	3 (12.0)			
n/a	7 (2.4)	0 (0.0)			

^{*} p<.05

There was a statistically significant inter-group difference with respect to behavioral difficulties as a reason for ER consultation, X^2 (1, N=301) = 41.25 p <.001 with a small effect size ($\phi=0.37$). That is, youth with ASD were more likely to present to the ER with behavioral difficulties than their peers without ASD. Results for the various reasons for ER consultation are presented in Table 3.

Table 3 Reasons for ER consultation per participant

Characteristics	Neurotypical	Autistic	X ²	р	φ
	(Non-ASD)	(ASD)			
	N = 286	N = 25			
Suicide attempts, n(%)			1.18	.277	.063
Without	263 (92.0)	24 (96.0)			
With	13 (4.5)	0 (0.0)			
n/a	10 (3.5)	1 (4.0)			
Behavior problems, n(%)			41.25	<.001*	.037
Without	260 (90.9)	13 (52.0)			
With	17 (5.9)	11 (44.0)			
n/a	9 (3.2)	1 (4.0)			
Anxiety/panic, n(%)			.37	.542	.035
Without	243 (85.0)	22 (88.0)			
With	35 (12.2)	2 (8.0)			
n/a	8 (2.8)	1 (4.0)			
School refusal, n(%)			.80	.371	.051
Without	269 (94.1)	24 (96.0)			
With	9 (3.1)	0 (0.0)			
n/a	8 (2.8)	1 (4.0)			
Mood dis/depres. sx, n(%)			.20	.653	.026
Without	221 (77.3)	20 (80.0)			
With	57 (19.9)	4 (16.0)			
n/a	8 (2.8)	1 (4.0)			
Nonsuicidal s-injury, n(%)			1.56	.212	.072
Without	261 (91.3)	24 (96.0)			
With	17 (5.9)	0 (0.0)			
n/a	8 (2.8)	1 (4.0)			
Alcohol/drugs use, n(%)			0.44	.508	.038

Without	274 (95.8)	24 (96.0)			
With	5 (1.8)	0 (0.0)			
n/a	7 (2.4)	1 (4.0)			
Psychopathology n(%)			1.46	.227	.069
Without	261 (91.3)	21 (84.0)			
With	17 (5.9)	3 (12.0)			
n/a	8 (2.8)	1 (4.0)			
Homicidal idea., n(%)			.17	.677	.024
Without	276 (96.5)	24 (96.0)			
With	2 (0.7)	0 (0.0)			
n/a	8 (2.8)	1 (4.0)			
Other non-psych, n(%)			1.36	.243	.067
Without	263 (92.0)	24 (96.0)			
With	15 (5.2)	0 (0.0)			
n/a	8 (2.8)	1 (4.0)			

^{*} p<.001

2.5 Discussion

Similar to literature findings which describe a male sex predominance of ASD in the community (Public Health Agency of Canada, 2012; Public Health Agency of Canada, 2018), results of this study showed a significant difference for sex, with over half of the ASD group who sought crisis intervention being male (17 males: 7 females). We can make sense of these results by considering the findings of Mandy et al. (2012) who indicate that sex differences with regards to symptoms observed tend to resemble the sex differences observed in the general population. Given that males tend to display more externalizing behaviors such as aggression, hyperactivity and impulsivity (Mandy et al., 2012), they are more likely to be targeted, offering a possible explanation as to why males are diagnosed earlier than females. This idea was also supported by this study's findings, demonstrating behavioral difficulties to be significantly greater as a reason for ER consultation compared to those without ASD. This is especially true if presenting to the ER in behavioral crisis is their only means of communicating a need for medical assistance, as suggested by Buie et al. (2010).

Moreover, difficulties arise when these challenging behaviors exhibited by males with ASD become so problematic that they surpass a threshold of acceptable behavior. When these youth are socially disruptive such as in a school setting with limited support services, functioning and integration becomes compromised. Given that females tend to exhibit more internalized behaviors such as anxiety, depression and withdrawal (Mandy et al., 2012; Solomon et al., 2012), their symptoms may be viewed as less disruptive and go unnoticed. Their "quiet" suffering may be masking distress, precluding access to help

and resulting in reduced ER admissions for young females with ASD. Hence, it is important for all community caregivers to be cognisant of the particular symptom profile of females with ASD for early recognition and intervention.

The majority of children receive an ASD diagnosis before the age of 5 (Public Health Agency of Canada, 2022). The findings of this study reflect a similar pattern, showing a significantly younger age among those with ASD presenting to the ER. Several possibilities may explain these findings. First, it may be that children are being diagnosed younger now than previously (Southwest Autism Research & Resource Center, 2018) and therefore, we are seeing children already diagnosed with ASD present to the ER in crisis at younger ages. Another possibility may be that given the lack of specialized services available for this population, families turn to the ER for support when in crisis. In Québec, it can take up to 2 years or longer to receive intervention services after obtaining a diagnosis of ASD (Hendry, 2016). Without access to services, it can be expected that problematic behaviors are exasperating; and with long lapses of time without help, families find themselves in crisis. This becomes even more problematic once a child starts school, and is still on a waitlist to receive intervention. When behaviors become unmanageable in a school context, it is not uncommon for students to be sent to the ER due to problematic behavior, only to be sent back without follow-up services. Evidently, difficult behaviors begin again, only to find these children being sent back to the ER (Chatterjee & Herman, 2021).

Despite mixed findings on the relationship between ASD and parental marital status, the present results aligned with the findings of Baeza-Velasco et al. (2013) and Freedman et al. (2012) who reported no significant evidence of a relationship between the two. Our results revealed that families of youth with ASD who visit the ER in crisis were not any more likely to emanate from households of divorce or separation than peers without the diagnosis. One might expect a higher prevalence of couple conflict in circumstances of stress introduced when managing the behavioral challenges of a child with ASD (Estes et al., 2009; Risdal & Singer, 2004). Several potential explanations can be offered for this finding. On the one hand, such families may be more proactive in seeking couple counseling. As well, the stresses that come with an autistic youth in crisis are likely to impact all families, separated or intact, thus neutralizing any potential differential impact on help-seeking among these couples. As well, any premorbid couple condition (i.e. financial, medical or psychiatric, to name a few) that compromises the couple's functioning would also render them particularly vulnerable when caring for a high-needs child. All things considered, it is incumbent on healthcare providers to be particularly cognizant of these family stressors and to address

them whenever possible (i.e. through family and/or couple counselling) to ensure a more promising outcome in caring for their autistic child.

Findings on the association between ASD and family SES are mixed, however, our results align with those of Larsson et al. (2005) who found no association between the two. With that said, despite our results revealing that no families of high SES from the ASD group came to the ER for crisis intervention, there were notably few high SES families in the neurotypical group as well. This comes as no surprise, and supports findings of Bartram (2019) in that families of higher SES typically have easier access to more costly private services and are less likely to use emergency services than families of lower SES, who cannot afford such services (Smith et al., 2020). Thus, income disparities appear to be correlated with access to health care services, as proposed in the literature by Larson and Halfon (2010).

Mental health concerns of youth are of paramount concern (Burstein et al., 2019; Dolan et al., 2011; Mapelli et al., 2015; Newton at al., 2016; Sills & Bland, 2002) and even more so for youth with ASD (Beverly et al., 2021; Kalb, et al., 2012; Kogan et al., 2008). Although we found no clinically significant difference between the psychosocial functioning of those with and without ASD, more than half of the ASD group presented with CGAS scores below 50, depicting low psychosocial functioning and consistent with the poor functioning of all youth presenting in crisis to the ER (Greenfield et al., 2002). This finding also validates the behavioral and social challenges that beset this vulnerable population, which often extend beyond the diagnosis itself, often including comorbidity, and underlining their need for adequate mental health and social services.

Services are sparse for youth with ASD as they are for all youth. This is particularly problematic as, consistent with prior reports (Bardon et al., 2015; Kõlves, et al., 2021; Rybczynski et al., 2022; Zahid & Upthegrove, 2017), results demonstrate that youth with ASD, versus those without the diagnosis, are at higher risk of suicidal behaviors and thus more likely to present to the ER for crisis support. To add to their burden, their communication struggles and social deficits make it challenging for them to identify and express their emotions and to seek help and social support. Having co-existing mental illness also puts them at greater risk of psychosocial dysfunction (Joshi et al., 2010; McCarthy, 2007; Rossetti, 2020), increasing their suicidal behavior (Kõlves, et al., 2021). As well, we still tend to under-diagnose their comorbid psychiatric disorders (Levy et al., 2010; Rossetti, 2020), further increasing their vulnerability. With suicide being the second leading cause of death among youth aged 10-19 (Centers for Disease Control

and Prevention, 2019), and an even greater risk for those with ASD (Kõlves, et al., 2021; Rybczynski et al., 2022; Zahid & Upthegrove, 2017), families and care providers need to be able to identify the risk factors, evaluate needs and gain expedited access to specialized services for these youth.

Findings of Joshi et al. (2010) and McCarthy (2007) demonstrate a higher risk of mental health issues and co-existing psychiatric disorders in those with versus those without ASD. On the contrary, our results did not support such findings, with the exception of substance use disorder which was found to be significantly higher in the Non-ASD group. First, the absence of differences between ASD and Non-ASD groups may be related to the fact that patients with ASD have the same psychopathology profile as has been reported in the literature, but our Non-ASD population appears sicker than what has been reported by virtue of their being in psychiatric crisis presenting to the ER. The above would dilute the difference in the appearance of co-existing psychiatric disorders between the two groups in this sample. Second, the lack of group differences may also be explained by the presence of diagnostic overshadowing, whereby healthcare practitioners may be misattributing presenting difficulties to the autism alone, without considering the possibility of a psychiatric disorder in addition to the autism (Rossetti, 2020). As a result, comorbid psychiatric disorders are not diagnosed, compromising proper treatment for the individual with ASD. In addition, this lack of inter-group differences could also be explained by the influx into the ER of many children. This would include those not acutely in crisis and those for whom crisis was inevitable due to the scarcity of community-based services, and perhaps neutralizing group differences. As mental health issues in youth have risen over the years, and services to help these children become depleted and scarce, families find themselves urgently seeking help at the hospital.

Results of a decreased use of drugs for those with ASD support findings of Arnevik and Helverschou (2016) and Ramos et al. (2013). These results are not surprising, given that children with ASD have limited social networks and are thus generally less likely to be influenced by peers who are experimenting with substances. As well, their tendency toward concrete thinking and literal interpretation of social rules makes them less likely to break rules and engage in risky behaviors (Ramos et al., 2013). Their social and communication deficits may even be viewed as a protective factor for substance use disorder (Santosh & Mijovic, 2006).

2.6 Limitations and Future Research

This study is not without limitations. First, given that our target population was restricted to participants who had access to the Montreal Children's Hospital ER, the data retrieved was only on a portion of the population, and may not be an accurate representation of all autistic youth seeking crisis consultation. Second, it is noteworthy that the bulk of recruitment occurred three days per week over a one-year period, corresponding to the availability of the project coordinator of the gene-environment study. The option to continue recruiting over several more years was solely an administrative expediency that was not implemented and thus did not accurately reflect the true frequency of youth with ASD presenting in crisis to the ER. Also, given the small number of participants constituting the ASD group, results may be limited and not generalizable to the entire autistic population impacting the external validity of the study. Furthermore, this retrospective study may not have captured all autistic patients who visited the ER, and the information obtained was dependent solely on the written documentation noted in the medical charts. Having had the opportunity to incorporate different measures of gathering information from participants may have provided us with more precise and accurate information. Lastly, given the disproportionate group sizes, all levels of ASD were grouped together within the same group. The study may have reflected different results if participants were grouped by ASD level, as the variability of functioning within the ASD group may not have been homogeneous. Having grouped the autistic participants by level may have generated a more accurate representation of socio-demographic and clinical profiles based on the variable levels of functioning.

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CHAPTER 3

GENERAL DISCUSSION

To the best of our knowledge, this is the first study to explore and compare the socio-demographic and clinical variables between autistic and neurotypical children that present to a metropolitan pediatric emergency room for crisis intervention in Montreal, Québec.

The current study sought to identify the specific profiles of youth with ASD who present to the Montreal Children's Hospital, in order to quickly and efficiently identify their needs when they present to the ER in crisis. Having this understanding will help improve management, orient service delivery and inform governmental organizations of the need to provide service accessibility to this vulnerable population.

Results of this study indicate that children with ASD who present to the ER showed a higher frequency of male sex, greater prevalence of behavioral disorders as the reason for ER consultation, and with increased suicidal behavior. Despite mixed literature findings, youth with ASD presented to the ER at a younger age, and with no differences in parental marital status, socio-economic status or psychosocial functioning compared to those without ASD. Each of these findings will be discussed in greater detail below.

3.1 Sex Differences in Diagnosing ASD

Males are more often diagnosed with ASD than females in the general population (Fombonne, 2009; Public Health Agency of Canada, 2018, 2022), however, it is unclear if this discrepancy is due to sex differences in rates of ASD, underdiagnosis of females (Halladay et al., 2015; Hull et al., 2020; Loomes et al., 2017), camouflaged symptomology (McCrossin, 2022), or because of later diagnosis in females than males (May & Williams, 2018), delaying their opportunity to receive early intervention services (Chellew et al., 2022). Given that females generally exhibit more internalized behaviors such as anxiety, depression and withdrawal (Mandy et al., 2012; Solomon et al., 2012), their symptoms may be viewed as less disruptive and go unnoticed. The risk with females is that their "quiet" suffering may be masking distress, precluding access to help and resulting in reduced ER admissions for young autistic females. Some evidence suggests that females may not be identified because they express their condition in ways that do not meet the current diagnostic criteria (Hull et al., 2020). Hence, it is important for all community caregivers to be cognisant of the particular symptom profile of females with ASD for early recognition and intervention.

Similar to literature findings that characterize male sex predominance of ASD in the community, results of the current study demonstrated a clinically significant difference for sex, with more than half of the ASD group who utilized ER services for crisis intervention being male (17 males: 7 females). We can make sense of these results by considering the work of Mandy et al. (2012) who indicate that sex differences with regards to symptoms observed tend to resemble the sex differences observed in the general population. Given that boys, in general, tend to engage in more externalizing behaviors including aggressive acts, hyperactive and impulsive behaviors, it is not surprising that they are more likely to be identified to get help more quickly and urgently. Moreover, this idea further supports this study's findings demonstrating behavioral difficulties to be significantly higher as a reason for ER consultation, compared to peers without the diagnosis. This is especially true if presenting to the ER in behavioral crisis is the only means in which youth with ASD can communicate a need for medical assistance, as suggested by Buie et al. (2010). Furthermore, challenges become apparent when the difficult behaviors displayed by males with ASD surpass a threshold of acceptable behavior. When autistic youth are socially disruptive such as in a daycare or school setting with limited support services, functioning and integration becomes compromised.

3.2 Young Autistic Youth in the ER

The literature depicts that the majority of children receive an ASD diagnosis around the age of 5, and the highest prevalence of the disorder was for children aged 5-11 (Public Health Agency of Canada, 2022). Findings of the present study reflect a similar pattern, demonstrating that autistic youth who come to the ER for crisis intervention are of a significantly younger age than their peers without the disorder. Several possibilities may explain the current findings. First, it may be that children are being diagnosed younger now than previously (Southwest Autism Research & Resource Center, 2018) and as a result, we are seeing children of younger ages already with a diagnosis present to the ER in crisis. Another explanation may be that due to the delays in access to specialized intervention services for youth with ASD, families are turning to the ER for crisis management. In Quebec, it can take up to 2 years or longer to receive intervention services after obtaining a diagnosis of ASD (Hendry, 2016). Without any intervention for these children, it can be expected that problematic behaviors will exacerbate; and with long lapses of time without help, families find themselves in crisis. An even bigger problem is when the child with ASD has become school aged, and still awaiting services. When behaviors become unmanageable in a school context, it is not uncommon for children to be sent to the ER due to these challenging behaviors, only to be sent back without follow-up services. Evidently, difficult behaviors begin again, only to find these students being sent back to the ER (Chatterjee & Herman, 2021), and families find themselves in a vicious cycle with minimal progress.

3.3 Parents of Autistic Youth

Negative psychological effects such as depression, anxiety and stress are common outcomes for parents of children with disabilities (Boyce et al., 1994; Reichman et al., 2008; Rezendes & Scarpa, 2011). An inverse relationship exists between the behavioral problems of children with neurodevelopmental disorders and family functioning and is often mediated by depressive symptoms in parents (Jellett et al., 2015). Families are often negatively impacted while trying to manage the behavioral difficulties of their children with neurodevelopmental disorders, which consequently increases stress levels in family members. In fact, these families, notably those with combined ASD and intellectual disability (ID), reported the highest amount of family stress despite receiving the majority of psychosocial support, as contrasted with those with only ASD or ID. These findings were not surprising given that youth with comorbid conditions often exhibit more behavioral difficulties, less adaptive behaviors and fewer social skills (Morin et al., 2014).

Although the literature reflects mixed findings on the relationship between ASD and parental marital status, the present results aligned with the findings of Freedman et al. (2012) who reported no significant evidence of a relationship between the two. The current study showed that youth with ASD who visit the ER in crisis were not any more likely to emanate from households of divorce or separation than peers without the diagnosis. One might expect a higher prevalence of couple conflict in circumstances of distress when trying to parent and manage the behavioral challenges of a child with ASD (Estes et al., 2009; Risdal & Singer, 2004). Several potential explanations can be offered for this finding. On the one hand, it is possible that such families are more proactive in seeking couple counseling, increasing the chances of remaining together despite the stress. As well, the stresses that come with an autistic child in crisis are likely to impact all families, separated or intact, thus neutralizing any potential differential impact on help-seeking among these couples. All things considered, it is incumbent on healthcare professionals to be particularly cognizant of the risks of these family stressors and to address them whenever possible (i.e. through family and/or couple counselling) to ensure a more promising outcome in caring for their child with ASD.

3.4 Socio-Economic Status

Although the literature depicts mixed findings on the association between youth ASD and family SES, results of this study align with findings of Larsson et al. (2005) who found no association between the two. With that said, despite our results revealing that no families of high SES from the ASD group came to the ER for crisis intervention, there were notably few high SES families in the neurotypical group as well. It is

not surprising and supports findings of Bartram (2019) in that families of higher SES typically have easier access to more costly private services and are less likely to use emergency services than our families of lower SES, who cannot afford such services (Smith et al., 2020). Thus, one can speculate that income disparities may be correlated with access to health care services, as proposed in the literature by Larson and Halfon (2010).

3.5 Psychosocial Functioning and Mental Illness

The mental health of youth today is of great concern, and particularly for those with ASD (Burstein et al., 2019; Dolan et al., 2011; Mapelli et al., 2015; Newton et al., 2016; Sills & Bland, 2002). The current study results depict no clinically significant difference between the psychosocial functioning of those with and without ASD, with more than half of the ASD group presenting with CGAS scores below 50. Results of this study support findings of Greenfield at al. (2002) who indicate that low psychosocial functioning is prevalent among all youth who present to the ER in crisis. It is therefore not surprising to see that both groups would present with similar psychosocial functioning, with those in the neurotypical group presenting with lower psychosocial functioning than what we would see in the general population. One may also speculate that the accompanying challenges that beset those with ASD often extend beyond the diagnosis itself and highlight the needs for both mental health and support services.

Although the literature demonstrates a higher risk of mental health disorders and co-existing psychiatric conditions in those with versus without ASD (Joshi et al., 2010; McCarthy, 2007), the current study results did not support such findings. It can be expected given that the participants in our sample, both with ASD and without, are those who are presenting to an ER. This lack of inter-group differences could be explained by the influx into the ER of many youths. This would include those not acutely in crisis and those for whom crisis was inevitable due to the scarcity of community-based services, and perhaps neutralizing group differences. As mental health issues in youth have risen over the years, and services to help these children become depleted and scarce, families find themselves urgently seeking help at the hospital.

A significant difference was found between groups for substance use disorder, which was found to be significantly higher in the Non-ASD group. Although the literature demonstrates mixed findings on the commonality of an ASD and substance use disorder co-existence, results of a decreased use of drugs supporting findings of Arnevik and Helverschou (2016) and Ramos et al. (2013) are not surprising. Youth with ASD have limited social networks and are thus generally less likely to be influenced by peers who are

experimenting with substances. As well, their tendency toward concrete thinking and literal interpretation of social rules makes them less likely to break rules and engage in risky behaviors (Ramos et al., 2013). Their social and communication deficits may even be viewed as a protective factor for substance use disorder (Santosh & Mijovic, 2006).

3.6 Psychiatric Comorbidities and Increased Suicidal Behavior

Evidence shows an association between psychiatric disorders and suicidal behavior (Sher, 2019). Research investigations in the United States determined that over 90% of suicide victims have psychiatric disorders (Sher, 2019), yet over two thirds of suicide victims have never received mental health treatment (Stene-Larsen & Reneflot, 2019). Evidently, when psychiatric conditions remain untreated, the risk of suicide is even greater (Tang et al., 2022), especially for youth with ASD (Kõlves et al., 2021).

The results of our study are consistent with prior reports demonstrating that youth with ASD, versus those without the diagnosis, are at higher risk of suicidal behaviors (Bardon et al., 2015; Kõlves et al., 2021; Rybczynski et al., 2022; Zahid & Upthegrove, 2017). With mental health services lacking for this vulnerable group, it is not surprising that these youth present to the ER for crisis intervention and increased suicidal behavior. To add to their burden, communication and social deficits of those with ASD make it challenging for them to identify and express their emotions and to seek help and social support. Having co-existing mental illness also puts them at greater risk of psychosocial dysfunction (Joshi et al., 2010; McCarthy, 2007), increasing their suicidal behavior (Kõlves et al., 2021). With suicide being the second leading cause of death among youth aged 10-19 (Centers for Disease Control and Prevention, 2019) and an even greater risk for those with ASD (Kõlves et al., 2021; Rybczynski et al., 2022; Zahid & Upthegrove, 2017), families and clinicians need to be able to promptly identify the risk factors, evaluate needs and gain access to specialized services for these youth as quickly as possible.

3.7 Limitations

Although this study successfully met our research objective, a number of limitations should be considered. Firstly, regarding generalizability of results, the data collected was only on patients from the Montreal Children's hospital ER. Given that this data is only on a portion of the population, it may not be an accurate representation of all autistic youth who are seeking psychiatric crisis consultation. In addition, the limited number of participants in our ASD group may also limit the generalizability of results, impacting the

external validity of this study. Secondly, given the nature of this retrospective study, it may not have included all patients with ASD who presented to the ER and furthermore, information obtained is solely dependent on the written documentation to which we had access to, as noted in the medical charts. Thus, other important sociodemographic and clinical factors of ASD that are often highlighted in the literature but were not explored in this study such as comorbid physical health problems, sleep disturbances, medications used, and age of parents would have been pertinent variables to explore when comparing group differences. As well, given that Montreal is a bilingual, multicultural city, it would have also been beneficial to include ethnicity, cultural background, and languages spoken as variables in this study. Furthermore, having utilized additional methods of gathering information from patients to compensate for any data that was missing or not reported may have provided us with more precise and detailed information. For instance, although the CGAS is used as a standard measure of assessing the global functioning of patients who are seen at the Montreal Children's hospital for psychiatric assessment, the CGAS may not be the best measure for our autistic youth given the nature and severity of ASD-related impairments and atypical developmental trajectories commonly observed in those with ASD (Wagner et al., 2007). Rather, the DD-CGAS may have been a more appropriate measure, as it uses language that reflects a wide range of developmental levels and focuses specifically on 4 domains of functioning: self-care, communication, social behavior, and academic performance (Wagner et al., 2007). Thirdly, given the disproportion group sizes, patients with different ASD severity levels were included in the same group. Given the variability of functioning between levels, it may be that the ASD group was not homogeneous. Having grouped the autistic participants by level may have generated a more accurate representation of socio-demographic and clinical profiles based on the variable levels of functioning.

3.8 Recommendations and Conclusion

Although our study focuses on the necessity of identifying the socio-demographic and clinical characteristics of autistic youth presenting to the ER, an important consideration for future research is to not only focus on properly identifying this group and their needs, but to further evaluate the quality of services accessible within the ER. We have emphasized the importance of health care professionals recognizing these profiles, however it does not speak to the quality of the services that can be provided given the variability of training and specialization within the Mental Health Emergency Team, as well as the limitations in the context of an ER setting. Evaluating quality of services can help in implementing proper training of ER staff to better service this vulnerable population.

Our research has identified socio-demographic and clinical characteristics of the autistic population that is likely to present to the ER for crisis intervention in the Montreal area. Our hope is that our findings could also shed light on the urgent need to support youth with ASD; that with the scarcity of community-based health care services in Quebec, these youth and their families are faced with a crisis, having no choice but to seek overburdened emergency services in desperation. Identifying the autistic profiles quickly and efficiently can increase the chance of early intervention, which is key to better servicing, increasing prevention and improving overall outcomes for youth with ASD.

APPENDIX A

ETHICS APPROVAL CERTIFICATES



No. de certificat: 3555

Certificat émis le: 14-05-2019

CERTIFICAT D'APPROBATION ÉTHIQUE

Le Comité d'éthique de la recherche pour les projets étudiants impliquant des êtres humains (CERPE FSH) a examiné le projet de recherche suivant et le juge conforme aux pratiques habituelles ainsi qu'aux normes établies par la Politique No 54 sur l'éthique de la recherche avec des êtres humains (Janvier 2016) de l'UQAM.

A demographic comparison of emergency room utilization for psychiatric consultation between children with and without a neurodevelopmental disability Titre du projet:

Tania VIVIANI Nom de l'étudiant:

Programme d'études: Doctorat en psychologie (profil professionnel)

Direction de recherche: Diane MORIN Brian GREENFIELD Codirection:

Modalités d'application

Toute modification au protocole de recherche en cours de même que tout événement ou renseignement pouvant affecter l'intégrité de la recherche doivent être communiqués rapidement au comité.

La suspension ou la cessation du protocole, temporaire ou définitive, doit être communiquée au comité dans les meilleurs

Le présent certificat est valide pour une durée d'un an à partir de la date d'émission. Au terme de ce délai, un rapport d'avancement de projet doit être soumis au comité, en guise de rapport final si le projet est réalisé en moins d'un an, et en guise de rapport annuel pour le projet se poursuivant sur plus d'une année. Dans ce dernier cas, le rapport annuel permettra au comité de se prononcer sur le renouvellement du certificat d'approbation éthique.

Anne-Marie Parisot

Professeure. Département de linguistique

Présidente du CERPÉ FSH



2019-03-19

Dr. Brian Greenfield

c/o: Tania Viviani

email: viviani.tania@hotmail.com

Re: MUHC Authorization (A demographic comparison of emergency room utilization for psychiatric consultation between children with and without a neurodevelopmental disability / 2019-4844)

"A demographic comparison of emergency room utilization for psychiatric consultation between children with and without a neurodevelopmental disability"

We are writing to confirm that the study mentioned above has received research ethics board approval and all required institutional approvals, namely:

· Access to pediatric health records

You are hereby authorized to conduct your research at the McGill University Health Centre (MUHC) as well as to initiate recruitment.

Please refer to the MUHC Study number in all future correspondence relating to this study.

In accordance with applicable policies it is the investigator's responsibility to ensure that certification to conduct clinical research.

Should you have any questions, please do not hesitate to contact the support for the Personne mandatée at personne.mandatee@muhc.mcgill.ca.

We wish you every success with the conduct of the research.

Sincerely.

Sheldon Severy Sheldon Levy

MUHC REB Coordinator for MUHC REB Co-chair mentioned above



No. de certificat : 2020-2760

Date: 2024-01-30

AVIS FINAL DE CONFORMITÉ

Le Comité d'éthique de la recherche pour les projets étudiants impliquant des êtres humains (CERPE FSH) a examiné le projet de recherche suivant et le juge conforme aux pratiques habituelles ainsi qu'aux normes établies par la *Politique No 54 sur l'éthique de la recherche avec des êtres humains* (avril 2020) de l'UQAM.

Titre du projet : A demographic comparison of emergency room utilization for psychiatric consultation between children with and without a neurodevelopmental disability

Nom de l'étudiant : Tania Viviani

Programme d'études : Doctorat en psychologie

Direction(s) de recherche : Brian Greenfield; Diane Morin

Merci de bien vouloir inclure une copie du présent document et de votre certificat d'approbation éthique en annexe de votre travail de recherche.

Les membres du CERPE FSH vous félicitent pour la réalisation de votre recherche et vous offrent leurs meilleurs voeux pour la suite de vos activités.

Sylvie Lévesque

Professeure, Département de sexologie

Présidente du CERPÉ FSH

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